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Gynaecological cancer follow-up national survey of current practice

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Key words: neoplasm, questionnaires, female continuity of patient care/standards, survivorship, neoplasm recurrence

Abstract

Objective
To establish a baseline of national practice for follow-up after treatment for gynaecological cancer.

Design
Questionnaire survey.

Setting
Gynaecological cancer centres and units.

Geographical location
UK

Participants
Members of the British Gynaecological Cancer Society and the National Forum of Gynaecological Oncology Nurses**.**

Interventions
A questionnaire survey was circulated to enquiring about schedules of follow-up, who provides it and what routine testing is used.

Outcome measures
To determine if follow-up could be modified to improve the survivorship experience for patients who have had previous gynaecological cancer.

Results
A total of 117 responses were obtained; 115 (98%) reported hospital scheduled regular follow-up appointments. Two involved General Practitioners. Follow-up was augmented or replaced by telephone follow-up in 29 (25%) and patient initiated appointments in 38 responses (32%). A total of 88 (68%) cancer specialists also offered combined follow-up clinics with other specialties. Clinical examinations for hospital based follow-up are mainly performed by doctors (67% for scheduled regular appointments and 63% for patient initiated appointments) while telephone follow-up care is provided in the majority by nurses (76%). Most respondents provide routine tests (76/117 (65%)), from which 66/76 (87%) reported carrying out surveillance tests for ovarian cancer, 35/76 (46%) for cervical cancer, 8/76 (11%) for vulval cancer and 7/76 (9%) for endometrial cancer. Usually patients were discharged after five years (82/117 (70%)), whereas three (3%) were discharged after four years, nine (8%) after three and one (1%) after two years.

Conclusions
Practice varied but most used a standard hospital based protocol of appointments for five years and routine tests were performed usually for women with ovarian cancer. A minority utilised nurse-led or telephone follow-up. General Practitioners were rarely involved in routine care. A randomised study comparing various models of follow-up could be considered.

289 words

Article summary

Article focus

- Follow-up after treatment for cancer is a resource intense area of clinical practice which does not have clear benefits for patients.
- Doctors and nurses involved in care for women with gynaecological cancer were invited to respond to a questionnaire survey.
- A survey is presented of current follow-up after treatment for gynaecological cancer in the UK.

Key messages

- There is a variation of follow-up practice throughout the UK.
- A minority used nurse led or telephone follow-up as opposed to a conventional series of hospital outpatient appointments to see a doctor.

Strengths and limitations of this study

- A strength is that this is the first study to report the use of patient initiated, specialist nurse or telephone follow-up for gynaecological cancer in the UK.
- A limitation is that four UK cancer networks did not respond.

Introduction

Traditionally, patients who have had treatment for cancer are kept on regular review in hospital out-patient clinics for a period of between five to 10 years after completion of their treatment. The aims may be to detect recurrence of tumour, to monitor late effects of treatment, to collect data and to offer patients an opportunity to raise concerns or anxieties arising from their cancer. The assumption behind this approach is that early detection of recurrence will be of benefit to the patient and that monitoring side-effects and anxieties will allow helpful interventions that will improve the patient's quality of life.

Routine follow-up is a time-consuming and expensive process with many hundreds of patients attending clinics in each hospital each year at an NHS tariff of £118 per visit (Department of Health, 2011). In Wales alone we estimate the cost of this follow up is in excess of £1m annually. If the object is the early detection of recurrent disease, studies investigating recurrence for breast cancer reported most recurrences presenting between scheduled clinic appointments (Pandya *et al*, 1985; Scanlon *et al*, 1980; Brøyn and Frøyen, 1982; Winchester *et al*, 1979; Zwaveling *et al*, 1987; Grunfeld *et al*, 1996) and gynaecological patients may wait for their next routine appointment to disclose their symptoms (Olaitan *et al*, 2001). A cost benefit analysis for endometrial carcinoma showed that one asymptomatic recurrence was detected in every 653 consultations (Salvesen *et al*, 1997). In a review of 12 studies, only 30% of endometrial cancer recurrences were asymptomatic and methods of follow-up were unrelated to survival (Fung-Kee-Fung *et al,* 2006). As around 20% of all female cancer survivors have had gynaecological malignancy a cost effective form of surveillance is important (Salani *et al,* 2011).

In clinical practice there appears to be no rationale available for any particular follow-up protocol (Sartori *et al,* 2010). Rapid access to oncological assessment at recurrence may be more important than offering frequent routine appointments. Given that patients wish to be cured of their disease and that different schedules of follow-up do not appear to have an impact upon survival, delegation of routine follow-up could be to other carers. Telephone consultations can free oncologists' clinic time and is convenient for patients. Follow-up may be in primary care, a hospital based nurse led clinic, by telephone or at the request of the patient. Despite its place in standard healthcare the benefits of routine follow-up following treatment for cancer has received little scrutiny and has rarely been subjected to formal assessment.

In order to determine a baseline of current practice for gynaecological cancer follow-up in the United Kingdom, we have performed a survey of cancer follow-up in gynaecological oncology. The aim is to investigate who performs follow-up, for what duration and how this is achieved to see if there is a possibility to improve the quality of care offered to patients after their cancer treatment.

Materials and methods

The follow-up survey was designed using the Bristol Online Survey (BOS) to provide electronic data capture and data management support to the questionnaire. The BOS is an easy-to-use survey tool, which allows developing, deploying and analysing surveys via the internet. The dataset was managed by the Information Systems Department at the North Wales Organisation of Randomised Trials (Bangor University). Data was anonymised and then exported to the databases held in SPSS ™ (version

18.0; SPSS, Chicago, IL). The e-survey targeted gynaecological cancer experts in all cancer networks in the United Kingdom. It was available online using an electronic web link from June to September 2012. An initial invitation email and a reminder with the web link were sent through the Principal Investigator (PI) distribution list of the British Gynaecological Cancer Society (BGCS) and National Forum of Gynaecological Oncology Nurses (NFGON) members. A news release published in June 2012 on the BGCS website also invited members to take part in the survey.

The investigators in consultation with the BGCS and a patient representative designed the questionnaire which was organised around three themes (see questionnaire in appendix). The first comprised questions related to practice setting (i.e. organisation and hospital) and respondent characteristics (i.e. profession and medical specialty). The second comprised questions related to the use of standard protocols for follow-up. The bulk of the questionnaire addressed information about the different schedules of follow-up and which surveillance tests were used routinely in follow-up practices for different type of cancers. We listed four possible types of follow-up appointments; clinician-led (traditional), nurse-led, telephone follow-up and patient initiated follow-up. Telephone follow-up appointments were defined as a pre-arrangement for a member of the cancer team to contact the patient by telephone without a need for the patient to attend hospital. Patient initiated follow-up was defined as practice where the patient is not followed-up in secondary care but seen only if the patient requests or initiates a contact, for example if they are worried about a suspicion of recurrent disease.

Most answers were recorded as a binary variable (yes/no answer) with additional, open text box response options throughout the questionnaire for comments and alternative suggestions.

Data was collated and presented as numbers and a percentage of applicable denominators. The geographical spread of responses was mapped. Textual answers were categorised and counted.

Results

Sample size and respondents characteristics

Responses were received from 118 experts in gynaecological cancer drawn from the membership of the BGCS and NFGON. Because the survey was conducted online with the request to take part distributed widely by email it is impossible to state how many had the opportunity to take part but did not. Therefore the response rate has not been calculated. Nonetheless we received responses from 86% (24/28) of the cancer networks in England and all cancer networks in Wales (two), Scotland (three) and Northern Ireland (one). One response was received from a surgical oncologist based in Greece who has been excluded from the study as the objective is assessing current practice of follow-up after gynaecological cancer treatment in the UK. Of the 117 cancer specialists included in the study, 71 (61%) worked in a cancer centre, 32 (27%) in a cancer unit and 12 (10%) reported working in both. Eighty-eight (75%) of the respondents were surgical oncologists. Fifteen (13%) were clinical oncologists and six (5%) were specialised in medical oncology. The majority of the respondents (83 (71%)) were doctors while nurses constituted less than a third of the sample (32 (27%)). Full results are presented in table 1.

Standard follow-up protocols

All respondents with the exception of one surgical oncologist (116/117 (99%)) reported that they had a standard follow-up protocol after completion of treatment. However all 30 networks providing responses had at least one respondent reporting having protocols for follow-up. The vast majority of respondents provided follow-up in secondary care, only two respondents (from different English cancer networks) reported that visits to primary care are part of their follow-up routine.

Most 87/116 (75%) of the respondents reported using different follow-up protocols for different tumour sites (eg. cervix and ovary) and 35/116 (30%) reported having a different protocol for different tumour types (eg. well or poorly differentiated). On a cancer network basis, identical protocols for different tumour sites were reported in 16 networks. Identical protocols for different tumour types were reported by respondents from 23 of the 24 English networks, both of the Wales networks, the Northern Ireland network, and one of the cancer networks in Scotland.

Composition follow-up appointments

All respondents in our sample reported they follow-up patients after completion of gynaecological cancer treatment. One hundred and fifteen (98%) reported hospital scheduled regular follow-up appointments from which the patient may be discharged if she remains disease free after a specified period of time. This follow-up was augmented or replaced by a telephone follow-up in 29 (25%) and patient initiated appointments in 38 responses (32%). A combination of regular, telephone or patient initiated follow-up was available from 33 respondents and of these 19 (58%) reported patients could attend either a medical or a nurse led clinic. However, 6/19 (32%) did not have a protocol to allocate patients to each clinic. For patient initiated appointments, 10/38 (26%) of the specialists did not have a protocol with contact details (eg. a secretary, Macmillan nurse or General Practitioner) for self-referrals. A total of 88/117 (68%) cancer specialists also offered combined follow-up clinics with other specialties (eg. combined surgical and medical oncology or surgical and clinical oncology clinics).

Virtually all respondents reported in the case of sudden events that symptomatic patients could arrange an appointment in less than two weeks. Seven (6%) respondents from five different cancer networks answered that their practices schedule urgent appointments in a period of two to four weeks, from which two of them also scheduled urgent patient initiated appointments in the same timeframe.

Follow-up in hospital is mainly performed by doctors (67% for scheduled regular appointments and 63% for patient initiated appointments) while telephone follow-up care is provided in its majority by nurses (76%). Full details are illustrated in table 2.

Duration of follow-up and surveillance tests

The survey asked respondents whether they perform any type of routine follow-up or surveillance test during follow-up. Routine tests are provided by 65% (76/117) of respondents, from which 87% (66/76) reported carrying out tests for ovarian cancer, 46% (35/76) for cervical cancer, 11% (8/76) for vulva

cancer and nine per cent (7/76) for endometrial cancer. In addition, respondents were asked to provide details of when these tests are performed but only a few responses were obtained. Table 3 shows the distribution of the different type of tests employed during follow-up.

CA125 measurement was the most frequently used test (60/66 (91%)) during follow-up of ovarian cancer patients followed by other blood tests (8/66 (12%)), eg. alpha-fetoprotein , carcino-embryonic antigen , CA19.9 and inihibin. The routine use of computed tomography and magnetic resonance imaging (MRI) scans for ovarian cancer were reported by 9/66 (14%) of the respondents (one respondent used both CT and MRI). Eight cancer specialists stated the CA125 test is performed at each visit. Another seven specialists reported the CA125 is performed every three months for the first year after completion of treatment, from which two of them reported they carry on with routine testing for the second year and four up to year five every six months.

The use of MRI (15/35 (43%)) was the most common investigation employed in the follow-up of cervical cancer with cervical or vaginal cytology being the second commonest method (14/35 (40%)). There was a wide variety of tests (8/35 (23%)) reported in the follow-up of this type of cancer. Two of the respondents stated they perform vault cytology for cervical cancer patients annually for a period of five years following hysterectomy, while three specialists reported carrying out the test at six and 18 months post-treatment.

Most respondents discharged their patients after five years of follow-up (82/117 (70%)), three (3%) after four years, nine (8%) after three and one (1%) after two years whereas 22/117 (19%) of respondents did not answer this question.

Discussion

The current survey is the first evidence reporting the extent of patient initiated, specialist nurse or telephone follow-up for gynaecological cancer in the UK. Our survey also shows that all gynaecological cancer networks providing responses have protocols for follow-up after treatment. Follow-up for patients treated for gynaecological cancer is mainly performed by doctors in secondary care. There are few routine tests undertaken during follow-up to detect recurrence and they show no consistency particularly for cervical cancer. Of the 35 respondents who requested tests for cervical cancer follow-up, 15 (43%) requested MRI and 14 (40%) requested cytology. Such variation is not surprising with the lack of evidence to guide clinical management. The exception is CA125 testing following treatment for ovarian cancer where 52% of all respondents recommended CA125 monitoring despite grade one evidence to demonstrate that routine CA125 measurements do not benefit asymptomatic patients having had ovarian cancer (Rustin *et al,* 2010). Furthermore, there appears to have been no recent change of this practice in our survey, as monitoring with CA125 testing was reported in 24 of the 34 networks (71%) whereas 67% of networks recommended such testing in an earlier survey (Kew and Cruickshank, 2006). Patient initiated follow-up was offered by 32% of respondents and telephone follow-up was offered by 25%. A large minority of patient initiated follow-up and combined follow-up schedules did not have protocols to guide practice. The most common duration of routine follow-up is for five years.

Vistad *et al* (2012) also published results of a web-based survey of practice amongst gynaecological oncologists across Europe and reported that 47% of the 375 respondents considered follow-up with General Practitioners to be acceptable. Other options for care were not considered and the response rate was thought to be below 20%. However there appears to be little or no evidence upon which to guide follow-up for gynaecological malignancy from the survey by Vistad *et al,* the earlier survey from the UK (Kew and Cruickshank, 2006) and from our work.

From other research, patients with previous ovarian cancer rated CA125 testing as the most important part of follow-up despite the knowledge that routinely measuring the CA125 value does not improve survival (Rustin *et al,* 2010). Furthermore knowledge of recurrence whether treatable or not appears useful to patients (Kew *et al,* 2009) and information should be provided to detail the scope and limitations of follow-up (Kew *et al,* 2007). Rapid access to oncological assessment at recurrence may be more important than offering frequent routine appointments. Given that patients wish to be cured of their disease and knowing that different schedules of follow-up do not have an impact upon survival, delegation of routine follow-up could be to other carers (Vistad *et al,* 2012). Follow-up may be in primary care, a hospital based nurse led clinic, by telephone or at the request of the patient. An individualised approach to follow-up is likely to be important to concentrate care for those perceived to be at a greater risk of recurrent disease or other issues of survivorship. This may include a risk assessment where there are effective interventions for physical, psychological and social issues as well as needs assessments which are clearly patient centred as defined by the National Cancer Survivorship Initiative (Watson *et al,* 2012) whilst bearing in mind that a minority of patients may be cured with further therapy. Follow-up has to be multidisciplinary, designed for risk of recurrence and with good communication between professional groups. Informed patient choice regarding mode and frequency of follow-up is important. Reducing the frequency of follow-up appointments may not place an increased demand upon unnecessary patient initiated extra hospital appointments and patients may prefer fewer appointments (Gulliford *et al,* 1997). The ideal time of advising a patient about a preferred form of follow-up is unclear but may be shortly after all modalities of treatment have been completed.

North Wales Organisation for Randomised Trials in Health in collaboration with several leading gynaecological oncologists has previously developed a proposal for a randomised study to assess the value of hospital follow-up of endometrial cancer (Follow-up in Gynaecological Cancer Units: RCT for Endometrium or FIGURE). The proposal was for a multicentre, randomised trial comparing standard (hospital) follow-up with patient initiated review. The endpoints were to be quality of life and survival with a planned recruitment of 2200 patients to detect an effect size of 0.2. Unfortunately, although the proposal was well received, it was impossible to agree a level of funding to allow the study to proceed. More recently the Endometrial Cancer Telephone Follow-up Trial (ENDCAT ISRCTN 75220876) has started. This is a study comparing traditional hospital follow-up with telephone follow-up by specialist gynaecology oncology nurses with primary outcomes of psychological morbidity and patient satisfaction. Again this is a randomised trial for endometrial cancers only and is at a single centre. It is currently recruiting to schedule and is due to close in 2014. A Trial between Two Follow-up Regimens with Different Intensity in Endometrial Cancer Treated Patients (TOTEM NCT00916708) is a further ongoing but multicentre randomised trial in Italy, comparing overall survival, progression free survival, complications, proportion of asymptomatic relapse and the proportion of patients completing each regimen for follow-up. It is due to close in 2015.

Current trial activity suggests a trial similar to FIGURE should be revisited but to include follow-up for more than one gynaecological cancer site. Practice has already begun to change to include patient initiated follow-up for gynaecological cancer patients but our survey has demonstrated that these changes are not yet widespread. However, the evidence base for changing practice to a less intensive follow-up programme for gynaecological cancer is poor and Vistad *et al* (2011) reported no randomised studies on this subject. The current scoping study has demonstrated that the vast majority of follow-up still reflects traditional patterns, with only about a third of practitioners incorporating more flexible follow-up routines into their practice. In our current constrained financial environment, to continue to use patterns of follow-up for gynaecological cancers which are neither evidence-based nor affordable is inappropriate. We aim to develop a suite of pilot and feasibility studies that may lead to a UK multicentre randomised controlled trial to assess the clinical benefits and costs of routine hospital follow-up in comparison with the patient being empowered to choose her preferred format of follow-up for most gynaecological cancers. This would incorporate information with contact details and about the possible symptoms of recurrence, with formal review only as and when required by the patient. The current survey is the first in this series in assessing current national practice.

2918 words

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Authors' roles

Simon Leeson	final manuscript preparation, review of data, design of questionnaire
Nick Stuart	draft script development, design of questionnaire
Yvonne Sylvestre	review of data
Liz Hall	draft script development
Rhiannon Whitaker	draft script development, review of data, design of questionnaire

Competing interest

No, there are no competing interests.

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Data sharing

The raw data has been archived at NWORTH Clinical Trials Unit and will be available to interested researchers by agreement with the Principal Investigator.

Table 1: Characteristics of respondents (N=117)

	N (%)
Region	
England	102 (87%)
Wales	7 (6%)
Scotland	5 (4%)
Northern Ireland	3 (3%)
Organisation	
Cancer centre	71 (61%)
Cancer unit	32 (27%)
Cancer unit &cancer centre	12 (10%)
O ther[1]	2 (2%)
Specialty	
Surgical oncology	73 (62%)
Medical oncology	6 (5%)
Clinical oncology	15 (13%)
Surgical &medical oncology	6 (5%)
Surgical &clinical oncology	1 (1%)
Surgical, medical &clinical oncology	8 (7%)
Other[2]	8 (7%)
Profession	
Medical	83 (71%)
Nursing	32 (27%)
Other[3]	2 (2%)

1. Includes gynaecology unit in a chemo centre (n=1) and hospital (n=1).
2. Includes clinical nurse specialist (n=2), nursing (n=2), gynaecology (n=2), gynaecology & surgical oncology (n=1) and pathology (n=1).
3. Includes consultant radiographer (n=1) and missing response (n=1).

Table 2: Type and frequency of occurrence of differing modes of follow-up

	Regular	Telephone	Patient initiated
Positive responses	115/117 (98%)	29/117 (25%)	38/117 (32%)
Urgent follow-up bookings			
< 2 weeks	108/115 (94%)	29/29 (100%)	35/38 (92%)
2 to 4 weeks	7/115 (6%)	0 (0%)	2/38 (5%)
Responsible for follow-up			
Doctors	77/115 (67%)	4/29 (14%)	24/38 (63%)
Nurses	0 (0%)	22/29 (76%)	2/38 (5%)
Doctors & nurses	36/115 (31%)	3/29 (10%)	11/38 (29%)
Other[1]	2/115 (2%)	1/29 (3%)	1/38 (3%)

1. Includes radiographer (n=1), consultant radiographer (n=1), for regular appointments; specialist radiographer (n=1) for telephone appointments and missing response (n=1) for patient initiated appointments.

Table 3: Frequency of surveillance tests reported by type of test and cancer type

	Ultrasound†	CA125	Other blood tests*	CT	MRI	Cytology	Other¶	Total
Ovarian	5	60	8	5	4	0	0	82
Cervical	1	0	4	0	15	14	3	37
Endometrial	1	1	0	0	1	1	0	4
Vulval	0	0	0	0	1	0	4	5

Key: CA125, cancer antigen 125; CT, computed tomography; MRI, magnetic resonance imaging.

† Ultrasound includes: abdominal and transvaginal ultrasound.

** Other blood tests includes: other tumour markers (n=8) for ovarian cancer and squamous cancer antigen (n=3) for cervical cancer.*

¶ Other includes: colposcopy (n=2) for cervical cancer and vulvoscopy (n=3) for vulval cancer.

Appendix: Gynaecological cancer follow-up survey of current practice

Introduction

Patients may appreciate the attention given to follow up after treatment for cancer yet the survival benefit of follow up is unclear. We are planning to review local practice to determine if follow up to detect recurrence at an early stage can improve survival. However a preliminary assessment of national practice would be ideal. A prospective study of follow up strategies may follow. We would appreciate a few minutes of your time as cancer specialists to complete the following questionnaire.

Questions

Q1. In which cancer network do you work?

Q2. Where do you work?

i. Cancer Centre
ii. Cancer unit
iii. Other (please specify)

Q3.Please enter name of the hospital (s)at which you work? (Optional)

Q4. Is your work within surgical, medical or clinical oncology or another discipline?

i. Surgical oncology
ii. Medical oncology
iii. Clinical oncology
iv. Imaging
v. Pathology
iv. Other (please specify)

Q4.a. What is your profession?

i. Medical
ii. Nursing
iii. Other (please specify)

Q5. Do you have a standard follow up protocol following completion of treatment for gynaecological cancer?

i. Yes
ii. No
iii. Don't know

Q5a. Do you have a different protocol for different tumour sites e.g. cervix and ovary?

i. Yes
ii. No
iii. Don't know

Q5b. Do you have a different protocol for different tumour types e.g. well or poorly differentiated?

i. Yes
ii. No
iii. Don't know

Q5c. Does the routine follow-up involve visits to primary care?

i. Yes
ii. No
iii. Don't know

Q6. Do you have regular follow-up appointments? Regular follow-up appointments here means an agreed schedule of visits from which the patient may discharge if she remains disease free after a specified period of time.

i. Yes
ii. No
iii. Don't know

Q6a. If so, when can you book urgent follow-up appointments for symptomatic patients?

i. In less than 2 weeks
ii. 2-4
iii. 4+ weeks
iv. Don't know

Q6b. Who provides the follow-up?

i. Nurses
ii. Doctors
iii. Don't know
iv. Other (please specify)

Q7. Do you have telephone follow-up appointments? A telephone follow-up appointment is an appointment pre-arranged for a member of the cancer team to contact the patient by telephone without a need for the patient to attend hospital.

i. Yes
ii. No
iii. Don't know

Q7a. If so when can you book urgent follow-up appointments for symptomatic patients?

i. In less than 2 weeks
ii. 2-4
iii. 4+ weeks
iv. Don't know

Q7b. Who provides the follow-up?

i. Nurses
ii. Doctors
iii. Don't know
iv. Other (please specify)

Q8. Do you have patient initiated follow-up appointments? Patient initiated follow-up is when the patent is not followed-up in secondary care but sees only if the patent requests (such as suspicion of recurrent disease).

i. Yes
ii. No
iii. Don't know

Q8a. Do you have a protocol for asking patients to self-refer with contact details (e.g. a secretary, Macmillan Nurse or her GP)?

i. Yes
ii. No
iii. Don't know

Q8b. If so, can urgent appointments for symptomatic patients be booked? To see the patient

i. In less than 2 weeks
ii. 2-4
iii. 4+ weeks
iv. Don't know

Q8c. Who provides the follow-up?

i. Nurses
ii. Doctors
iii. Don't know
iv. Other (please specify)

Q9. Do you have a combination of regular follow-up, telephone follow up and/ or patient initiated follow-up appointments?

i. Yes
ii. No
iii. Don't know

Q9a. Do you have a follow-up where patients attend either a medical or a nurse led clinic?

i. Yes
ii. No
iii. Don't know

Q9b. If yes, do you have a protocol to allocate patents to each clinic?

i. Yes
ii. No

Q10. Do you have combined follow-up clinics with other specialties (e.g. combined surgical and medical oncology, surgical and clinical oncology clinics?

i. Yes
ii. No
iii. Don't know

Q10a. If yes please specify

i. Clinical
ii. Medical
iii. Surgical oncology

Q11. During follow-up do you carry out certain blood tests (e.g. CA125), vault cytology or imaging such as CT or MR routinely for cases at a certain time interval?

i. Yes
ii. No
iii. Don't know

Q11a. Ovary

i. Yes
ii. No

Q11a.i. Please provide details of which tests and when these are usually carried if possible

Q11b. Cervix

i. Yes
ii. No

Q11b.i. Please provide details of which tests and when these are usually carried if possible

Q11c. Endometrium

i. Yes
ii. No

Q11c.i. Please provide details of which tests and when these are usually carried if possible

Q11d. Vulva

i. Yes
ii. No

Q11d.i. Please provide details of which tests and when these are usually carried if possible

Q11e. Other

i. Yes
ii. No

Q11e.i. Please provide details of which tumour site(s)

Q11e.i.i. Please provide details of which tests and when these are usually carried if possible

Q12. After how many years of follow up are patients usually discharged?

i. 1
ii. 2
iii. 3
iv. 4
v. 5
vi. 6
vii. 7
viii. 8
ix. 9
x. 10
xi. 10+
xii. Never
xiii. N/A
xiv. Other(please specify)

Q13. If we were to develop a larger study would your centre be prepared to participate?

i. Yes
ii. No

Q13a. If so please add contact details here or email Simon Leeson

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Gynaecological cancer follow-up: National survey of current practice in the UK

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Gynaecological cancer follow-up national survey of current practice

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Key words: neoplasm, questionnaires, female continuity of patient care/standards, survivorship, neoplasm recurrence

Abstract

Objective
To establish a baseline of national practice for follow-up after treatment for gynaecological cancer.

Design
Questionnaire survey.

Setting
Gynaecological cancer centres and units.

Geographical location
UK

Participants
Members of the British Gynaecological Cancer Society and the National Forum of Gynaecological Oncology Nurses**.**

Interventions
A questionnaire survey.

Outcome measures
To determine schedules of follow-up, who provides it and what routine testing is used for patients who have had previous gynaecological cancer.

Results
A total of 117 responses were obtained; 115 (98%) reported hospital scheduled regular follow-up appointments. Two involved General Practitioners. Follow-up was augmented or replaced by telephone follow-up in 29 (25%) and patient initiated appointments in 38 responses (32%). A total of 80 (68%) cancer specialists also offered combined follow-up clinics with other specialties. Clinical examinations for hospital based follow-up were mainly performed by doctors (67% for scheduled regular appointments and 63% for patient initiated appointments) while telephone follow-up was provided in the majority by nurses (76%). Most respondents provided routine tests (76/117 (65%)), from which 66/76 (87%) reported carrying out surveillance tests for ovarian cancer, 35/76 (46%) for cervical cancer, 8/76 (11%) for vulval cancer and 7/76 (9%) for endometrial cancer. Usually patients were discharged after five years (82/117 (70%)), whereas three (3%) were discharged after four years, nine (8%) after three and one (1%) after two years.

Conclusions
Practice varied but most used a standard hospital based protocol of appointments for five years and routine tests were performed usually for women with ovarian cancer. A minority utilised nurse led or telephone follow-up. General Practitioners were rarely involved in routine care. A randomised study comparing various models of follow-up could be considered.

273 words

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Article summary

Article focus

- Follow-up after treatment for cancer is a resource intense area of clinical practice which does not have clear benefits for patients.
- Doctors and nurses involved in care for women with gynaecological cancer were invited to respond to a questionnaire survey.
- A survey is presented of current follow-up after treatment for gynaecological cancer in the UK.

Key messages

- There is a variation of follow-up practice throughout the UK.
- A minority used nurse led or telephone follow-up as opposed to a conventional series of hospital outpatient appointments to see a doctor.

Strengths and limitations of this study

- A strength is that this is the first study to report the extent of patient initiated, specialist nurse or telephone follow-up for gynaecological cancer in the UK.
- A limitation is that four UK cancer networks did not respond.

Data sharing statement

The raw data has been archived at NWORTH Clinical Trials Unit and will be available to interested researchers by agreement with the Principal Investigator.

Introduction

Traditionally, patients who have had treatment for cancer are kept on regular review in hospital out-patient clinics for a period of between five to 10 years after completion of their treatment. The aims may be to detect recurrence of tumour, to monitor late effects of treatment, to collect data and to offer patients an opportunity to raise concerns or anxieties arising from their cancer. The assumption behind this approach is that early detection of recurrence will be of benefit to patients and that monitoring side-effects and anxieties will allow helpful interventions that will improve quality of life.

Routine follow-up is a time-consuming and expensive process with many hundreds of patients attending clinics in each hospital each year at an NHS tariff of £118 per visit (Department of Health, 2011). In Wales alone we estimate the cost of this follow up is in excess of £1m annually. If the object is the early detection of recurrent disease, studies investigating recurrence for breast cancer reported most recurrences presenting between scheduled clinic appointments (Brøyn and Frøyen, 1982; Grunfeld *et al*, 1996; Pandya *et al*, 1985; Scanlon *et al*, 1980; Winchester *et al*, 1979; Zwaveling *et al*, 1987) and gynaecological patients may wait for their next routine appointment to disclose their symptoms (Olaitan *et al*, 2001). There is no prospective randomised evidence to suggest follow-up improves survival for ovarian cancer and retrospective data only to guide follow-up strategies for cervical cancer (Kew *et al,* 2011; Elit *et al,* 2009). Also there is no evidence that intensive follow up improves survival for endometrial cancer (Agboola *et al,* 1997; Allsop *et al,* 1997; Gadducci *et al,* 2000; Owen and Duncan, 1996; Reddoch *et al,* 1995; Salvesen *et al,* 1997; Shumsky *et al,* 1994). A cost benefit analysis for endometrial carcinoma showed that one asymptomatic recurrence was detected in every 653 consultations (Salvesen *et al*, 1997). In a review of 12 studies, only 30% of endometrial cancer recurrences were asymptomatic and methods of follow-up were unrelated to survival (Fung-Kee-Fung *et al,* 2006). As around 20% of all female cancer survivors have had gynaecological malignancy a cost effective form of surveillance is important (Salani *et al,* 2011).

In clinical practice there appears to be no rationale available for any particular follow-up protocol (Sartori *et al,* 2010). Rapid access to oncological assessment at recurrence may be more important than offering frequent routine appointments. Given that patients wish to be cured of their disease and that different schedules of follow-up do not appear to have an impact upon survival, delegation of routine follow-up could be to other carers. Telephone consultations can free oncologists' clinic time and is convenient for patients. Follow-up may be in primary care, a hospital based nurse led clinic, by telephone or at the request of the patient. Despite its place in standard healthcare the benefits of routine follow-up following treatment for gynaecological cancer has received little scrutiny and has rarely been subjected to formal assessment.

In order to determine a baseline of current practice for gynaecological cancer follow-up in the United Kingdom, we have performed a survey of cancer follow-up in gynaecological oncology. The intention is to investigate who performs follow-up, for what duration and how this is achieved to see if there is a possibility to improve the quality of care offered to patients after their cancer treatment.

Materials and methods

The follow-up survey was designed using the Bristol Online Survey (BOS) to provide electronic data capture and data management support to the questionnaire. The BOS is an easy-to-use survey tool, which allows developing, deploying and analysing surveys via the internet. The dataset was managed by the Information Systems Department at the North Wales Organisation of Randomised Trials (Bangor University). Data was anonymised and then exported to the databases held in SPSS ™ (version 18.0; SPSS, Chicago, IL). The e-survey targeted gynaecological cancer secondary care practitioners (incorporating surgical and non-surgical specialists) in all cancer networks in the United Kingdom. It was available online using an electronic web link from June to September 2012. An initial invitation email and a reminder with the web link were sent through the Principal Investigator (PI) distribution list to all 401 members of the British Gynaecological Cancer Society (BGCS) and all 71 members of the National Forum of Gynaecological Oncology Nurses (NFGON). A news release published in June 2012 on the BGCS website also invited members to take part in the survey. It is possible that respondents could provide multiple replies but no two responses from the same network were identical.

The investigators in consultation with the BGCS and a patient representative designed the questionnaire which was organised around three themes (see questionnaire in appendix). The first comprised questions related to practice setting (i.e. organisation and hospital) and respondent characteristics (i.e. profession and medical specialty). The second comprised questions related to the use of standard protocols for follow-up. The bulk of the questionnaire addressed information about the different schedules of follow-up and which surveillance tests were used routinely in follow-up practices for different type of cancers. We listed four possible types of follow-up appointments; clinician led (traditional), nurse led, telephone follow-up and patient initiated follow-up. Telephone follow-up appointments were defined as a pre-arrangement for a member of the cancer team to contact the patient by telephone without a need for the patient to attend hospital. Patient initiated follow-up was defined as practice where the patient is not followed-up in secondary care but seen only if the patient requests or initiates a contact, for example if they are worried about a suspicion of recurrent disease.

Most answers were recorded as a binary variable (yes/no answer) with additional, open text box response options throughout the questionnaire for comments and alternative suggestions.

Data was collated and presented as numbers and a percentage of positive responses. For those questions composed of a subset of questions, the number of positive responses in the main question was used as the denominator for the subset. The geographical spread of responses was mapped. Textual answers were categorised and counted.

Results

Sample size and respondents characteristics

Responses were received from 118 experts in gynaecological cancer drawn from the membership of the BGCS and NFGON. Because the survey was conducted online with the request to take part

distributed widely by email it is impossible to state how many had the opportunity to take part but did not. Therefore the response rate has not been calculated. Nonetheless we received responses from 86% (24/28) of the cancer networks in England and all cancer networks in Scotland (three), Wales (two), and Northern Ireland (one). Each responding cancer network provided between one to 14 responses. One response was received from a surgical oncologist based in Greece who has been excluded from the study as the objective is assessing current practice of follow-up after gynaecological cancer treatment in the UK. Of the 117 respondents included in the study, 71 (61%) worked in a cancer centre, 32 (27%) in a cancer unit and 12 (10%) reported working in both. Eighty-eight (75%) of the respondents were surgical oncologists. Fifteen (13%) were clinical oncologists and six (5%) were specialised in medical oncology. The majority of the respondents (83 (71%)) were doctors while nurses constituted less than a third of the sample (32 (27%)). Full results are presented in table 1.

Standard follow-up protocols

All respondents with the exception of one surgical oncologist (116/117 (99%)) had a standard follow-up protocol after completion of treatment. However all 30 networks providing responses had at least one respondent reporting having protocols for follow-up. The vast majority of respondents provided follow-up in secondary care, only two respondents (from different English cancer networks) reported that visits to primary care are part of their follow-up routine.

Most 87/116 (75%) of the respondents reported using different follow-up protocols for different tumour sites (eg. cervix and ovary) and 35/116 (30%) reported having different protocols for different tumour types (eg. well or poorly differentiated). On a cancer network basis, different protocols for different tumour sites were reported from 29/30 (97%) networks. Different protocols for different tumour types were reported by respondents from 17/30 (57%) networks..

Composition follow-up appointments

All respondents in our sample reported they follow-up patients after completion of gynaecological cancer treatment. One hundred and fifteen (98%) reported hospital scheduled regular follow-up appointments from which the patient may be discharged if she remains disease free after a specified period of time. This follow-up was augmented or replaced by a telephone follow-up in 29 (25%) and patient initiated appointments in 38 responses (32%). A combination of all three forms of follow-up was reported by 11 respondents (a total of 54 respondents offered more than one modality of follow-up). Of these 18/54 (33%) reported that patients have an opportunity to attend either a medical or a nurse led clinic. However, 6/18 (33%) did not have a protocol to allocate patients to each clinic. For patient initiated appointments, 10/38 (26%) did not have a protocol with contact details (eg. a secretary, Macmillan nurse or General Practitioner) for self-referrals. A total of 80/117 (68%) cancer specialists from 27/30 networks (90%) also offered combined follow-up clinics with other specialties (eg. combined surgical and medical oncology or surgical and clinical oncology clinics).

Virtually all respondents reported in the case of sudden events that symptomatic patients could arrange an appointment in less than two weeks. Seven (6%) respondents from five different cancer networks answered that their practices schedule urgent appointments in a period of two to four

weeks, from which two of them also scheduled urgent patient initiated appointments in the same timeframe.

Follow-up in hospital was mainly performed by doctors (67% for scheduled regular appointments and 63% for patient initiated appointments) while telephone follow-up care was provided in its majority by nurses (76%). Full details are illustrated in table 2.

Duration of follow-up and surveillance tests

The survey asked respondents whether they perform any type of routine surveillance test during follow-up. Routine tests were requested by 65% (76/117) of respondents, from which 87% (66/76) requested tests for ovarian cancer, 46% (35/76) for cervical cancer, 11% (8/76) for vulva cancer and nine per cent (7/76) for endometrial cancer. In addition, respondents were asked to provide details of when these tests are performed but only a few responses were obtained. Table 3 shows the distribution of the different type of tests employed during follow-up.

CA125 measurement was the most frequently used test (60/66 (91%)) during follow-up of ovarian cancer patients. Other blood tests (8/66 (12%)), eg. alpha-fetoprotein , carcino-embryonic antigen , CA19.9 and inihibin were also requested. The routine use of computed tomography and magnetic resonance imaging (MRI) scans for ovarian cancer were reported by 9/66 (14%) of the respondents (one respondent used both CT and MRI). Eight respondents stated the CA125 test is performed at each visit. Another seven reported the CA125 is performed every three months for the first year after completion of treatment, from which two reported they carry on with routine testing for the second year and four up to the fifth year every six months.

The use of MRI (15/35 (43%)) was the most common investigation employed in the follow-up of cervical cancer with cervical or vaginal cytology being the second commonest method (14/35 (40%)). There was a wide variety of tests (8/35 (23%)) reported in the follow-up of this type of cancer. Two of the respondents stated they perform vault cytology for cervical cancer patients annually for a period of five years following hysterectomy, while three specialists reported carrying out the test at six and 18 months post-treatment.

Most respondents discharged their patients after five years of follow-up (82/117 (70%)), three (3%) after four years, nine (8%) after three and one (1%) after two years whereas 22/117 (19%) of respondents did not answer this question.

Discussion

The current survey is the first evidence reporting the extent of patient initiated, specialist nurse or telephone follow-up for gynaecological cancer in the UK. There were no respondents for four cancer networks and because the survey was online, a response rate could not be calculated. This could introduce a potential source of bias if the answers from respondents were not representative of their relevant professional communities. Different protocols for different tumour sites and types and the use of combined speciality follow-up clinics were more often reported from network responses than

for individual responses because network responses included respondents with at least one positive response in each network. Unfortunately we could not calculate the agreement level within networks because of the small numbers of respondents from each network. The lack of consistency of responses within networks is again a potential source of error. Our survey shows that all gynaecological cancer networks providing responses have protocols for follow-up after treatment. Follow-up for patients treated for gynaecological cancer is mainly performed by doctors in secondary care. Patient initiated follow-up was offered by 32% of respondents and telephone follow-up was offered by 25%. A large minority of patient initiated follow-up and combined follow-up schedules did not have protocols to guide practice. The most common duration of routine follow-up was for five years. There are few routine tests undertaken during follow-up to detect recurrence and they show no consistency particularly for cervical cancer. Of the 35 respondents who requested tests for cervical cancer follow-up, 15 (43%) requested MRI and 14 (40%) requested cytology. Such variation is not surprising with the lack of evidence to guide clinical management. The exception is CA125 testing following treatment for ovarian cancer where 52% of all respondents recommended CA125 monitoring despite grade one evidence to demonstrate that routine CA125 measurements do not benefit asymptomatic patients having had ovarian cancer (Rustin *et al,* 2010). Furthermore, there appears to have been no recent change of this practice in our survey, as monitoring with CA125 testing was reported in 24 of the 34 UK networks (71%) whereas 67% of networks recommended such testing in an earlier survey (Kew and Cruickshank, 2006). Respondents were asked not to include tests requested during treatment but tests could have been included as part of trial protocols.

Vistad *et al* (2012) also published results of a web-based survey of practice amongst gynaecological oncologists across Europe and reported that 47% of the 375 respondents considered follow-up with General Practitioners to be acceptable. Other options for care were not considered and the response rate was thought to be below 20%. However there appears to be little or no evidence upon which to guide follow-up for gynaecological malignancy from the survey by Vistad *et al,* the earlier survey from the UK (Kew and Cruickshank, 2006) and from our work.

From other research, patients with previous ovarian cancer rated CA125 testing as the most important part of follow-up (Kew *et al,* 2009) despite a lack of evidence of benefit from routine measurement of the CA125 value upon survival(Rustin *et al,* 2010). Furthermore knowledge of recurrence whether treatable or not appears useful to patients (Papagrigoriadis and Heyman, 2003) and information should be provided to detail the scope and limitations of follow-up (Kew *et al,* 2007). Rapid access to oncological assessment at recurrence may be more important than offering frequent routine appointments. Given that patients wish to be cured of their disease and knowing that different schedules of follow-up do not have an impact upon survival, delegation of routine follow-up could be to other carers (Vistad *et al,* 2012). Follow-up may be in primary care, a hospital based nurse led clinic, by telephone or at the request of the patient. An individualised approach to follow-up is likely to be important to concentrate care for those perceived to be at a greater risk of recurrent disease or other issues of survivorship. This may include a risk stratification where there are effective interventions for physical, psychological and social issues as well as needs assessments which are clearly patient centred as defined by the National Cancer Survivorship Initiative (Watson *et al,* 2012) whilst bearing in mind that a minority of patients may be cured with further therapy. Follow-up has to be multidisciplinary, designed for risk of recurrence and with good communication between professional groups. Informed patient choice regarding mode and frequency of follow-up is important. Reducing the frequency of follow-up appointments may not place an increased demand upon unnecessary patient initiated extra

hospital appointments and patients may prefer fewer appointments (Gulliford *et al,* 1997). The ideal time of advising a patient about a preferred form of follow-up is unclear but may be shortly after all modalities of treatment have been completed.

Healthcare providers should be informed by prospective data on the validity of alternative strategies for gynaecological cancer follow-up which is already a minority part of current UK practice. The North Wales Organisation for Randomised Trials in Health in collaboration with several leading gynaecological oncologists has previously developed a proposal for a randomised study to assess the value of hospital follow-up of endometrial cancer (Follow-up in Gynaecological Cancer Units: RCT for Endometrium or FIGURE). The proposal was for a multicentre, randomised trial comparing standard (hospital) follow-up with patient initiated review. The endpoints were to be quality of life and survival with a planned recruitment of 2200 patients to detect an effect size of 0.2. Unfortunately, although the proposal was well received, it was impossible to agree a level of funding to allow the study to proceed. More recently the Endometrial Cancer Telephone Follow-up Trial (ENDCAT ISRCTN 75220876) has started. This is a study comparing traditional hospital follow-up with telephone follow-up by specialist gynaecology oncology nurses with primary outcomes of psychological morbidity and patient satisfaction. Again this is a randomised trial for endometrial cancers only and is at a single centre. It is currently recruiting to schedule and is due to close in 2014. A Trial between Two Follow-up Regimens with Different Intensity in Endometrial Cancer Treated Patients (TOTEM NCT00916708) is a further ongoing but multicentre randomised trial in Italy, comparing overall survival, progression free survival, complications, proportion of asymptomatic relapse and the proportion of patients completing each regimen for follow-up. It is due to close in 2015.

Our study has demonstrated that the vast majority of follow-up still reflects traditional patterns, with only about a third of practitioners incorporating more flexible follow-up routines. However, the evidence base for changing practice to a less intensive follow-up programme for gynaecological cancer is poor and Vistad *et al* (2011) reported no randomised studies on this subject. A trial similar to FIGURE should be revisited but to include follow-up for more than one gynaecological cancer site. In the present constrained financial environment, to continue to use patterns of follow-up for gynaecological cancers which are neither evidence-based nor affordable is inappropriate. A multicentre randomised controlled trial could assess the clinical benefits and costs of routine hospital follow-up in comparison with the patient being empowered to choose her preferred format of follow-up for most gynaecological cancers. The current survey may inform design of such a trial by providing data from the UK concerning national practice.

3150 words

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Simon Leeson	final manuscript preparation, review of data, design of questionnaire
Nick Stuart	draft script development, design of questionnaire
Yvonne Sylvestre	review of data
Liz Hall	draft script development
Rhiannon Whitaker	draft script development, review of data, design of questionnaire

Table 1: Characteristics of respondents (N=117)

	N (%)
Region	
England	102 (87%)
Wales	7 (6%)
Scotland	5 (4%)
Northern Ireland	3 (3%)
Organisation	
Cancer centre	71 (61%)
Cancer unit	32 (27%)
Cancer unit & cancer centre	12 (10%)
Other[1]	2 (2%)
Specialty	
Surgical oncology	73 (62%)
Medical oncology	6 (5%)
Clinical oncology	15 (13%)
Surgical & medical oncology	6 (5%)
Surgical & clinical oncology	1 (1%)
Surgical, medical & clinical oncology	8 (7%)
Other[2]	8 (7%)
Profession	
Medical	83 (71%)
Nursing	32 (27%)
Other[3]	2 (2%)

1. Includes gynaecology unit in a chemotherapy centre (n=1) and hospital (n=1).
2. Includes clinical nurse specialist (n=2), nursing (n=2), gynaecology (n=2), gynaecology & surgical oncology (n=1) and pathology (n=1).
3. Includes consultant radiographer (n=1) and missing response (n=1).

Table 2: Type and frequency of occurrence of differing modes of follow-up

	Regular	Telephone	Patient initiated
Positive responses	115/117 (98%)	29/117 (25%)	38/117 (32%)
Urgent follow-up bookings			
< 2 weeks	108/115 (94%)	29/29 (100%)	35/38 (92%)
2 to 4 weeks	7/115 (6%)	0 (0%)	2/38 (5%)
Responsible for follow-up			
Doctors	77/115 (67%)	4/29 (14%)	24/38 (63%)
Nurses	0 (0%)	22/29 (76%)	2/38 (5%)
Doctors & nurses	36/115 (31%)	3/29 (10%)	11/38 (29%)
Other[1]	2/115 (2%)	1/29 (3%)	1/38 (3%)

1. Includes radiographer (n=1), consultant radiographer (n=1), for regular appointments; specialist radiographer (n=1) for telephone appointments and missing response (n=1) for patient initiated appointments.

Table 3: Frequency of surveillance tests reported by type of test and cancer type

	Ultrasound†	CA125	Other blood tests*	CT	MRI	Cytology	Other¶	Total
Ovarian	5	60	8	5	4	0	0	82
Cervical	1	0	4	0	15	14	3	37
Endometrial	1	1	0	0	1	1	0	4
Vulval	0	0	0	0	1	0	4	5

Key: CA125, cancer antigen 125; CT, computed tomography; MRI, magnetic resonance imaging.

† Ultrasound includes: abdominal and transvaginal ultrasound.

** Other blood tests includes: other tumour markers (n=8) for ovarian cancer and squamous cancer antigen (n=3) for cervical cancer.*

¶ Other includes: colposcopy (n=2) for cervical cancer and vulvoscopy (n=3) for vulval cancer.

Gynaecological cancer follow-up national survey of current practice

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Key words: neoplasm, questionnaires, female continuity of patient care/standards, survivorship, neoplasm recurrence

Abstract

Objective
To establish a baseline of national practice for follow-up after treatment for gynaecological cancer.

Design
Questionnaire survey.

Setting
Gynaecological cancer centres and units.

Geographical location
UK

Participants
Members of the British Gynaecological Cancer Society and the National Forum of Gynaecological Oncology Nurses.

Interventions
A questionnaire survey ~~was circulated to enquiring about schedules of follow-up, who provides it and what routine testing is used~~.

Outcome measures
To determine schedules of follow-up, who provides it and what routine testing is used ~~To determine if follow-up could be modified to improve the survivorship experience~~ for patients who have had previous gynaecological cancer.

Results
A total of 117 responses were obtained; 115 (98%) reported hospital scheduled regular follow-up appointments. Two involved General Practitioners. Follow-up was augmented or replaced by telephone follow-up in 29 (25%) and patient initiated appointments in 38 responses (32%). A total of 80~~8~~ (68%) cancer specialists also offered combined follow-up clinics with other specialties. Clinical examinations for hospital based follow-up were~~are~~ mainly performed by doctors (67% for scheduled regular appointments and 63% for patient initiated appointments) while telephone follow-up ~~care wai~~s provided in the majority by nurses (76%). Most respondents provided routine tests (76/117 (65%)), from which 66/76 (87%) reported carrying out surveillance tests for ovarian cancer, 35/76 (46%) for cervical cancer, 8/76 (11%) for vulval cancer and 7/76 (9%) for endometrial cancer. Usually patients were discharged after five years (82/117 (70%)), whereas three (3%) were discharged after four years, nine (8%) after three and one (1%) after two years.

Conclusions
Practice varied but most used a standard hospital based protocol of appointments for five years and routine tests were performed usually for women with ovarian cancer. A minority utilised nurse led or telephone follow-up. General Practitioners were rarely involved in routine care. A randomised study comparing various models of follow-up could be considered.

273 words

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Article summary

Article focus

- Follow-up after treatment for cancer is a resource intense area of clinical practice which does not have clear benefits for patients.
- Doctors and nurses involved in care for women with gynaecological cancer were invited to respond to a questionnaire survey.
- A survey is presented of current follow-up after treatment for gynaecological cancer in the UK.

Key messages

- There is a variation of follow-up practice throughout the UK.
- A minority used nurse led or telephone follow-up as opposed to a conventional series of hospital outpatient appointments to see a doctor.

Strengths and limitations of this study

- A strength is that this is the first study to report the extent~~use~~ of patient initiated, specialist nurse or telephone follow-up for gynaecological cancer in the UK.
- A limitation is that four UK cancer networks did not respond.

Data sharing statement

The raw data has been archived at NWORTH Clinical Trials Unit and will be available to interested researchers by agreement with the Principal Investigator.

Introduction

Traditionally, patients who have had treatment for cancer are kept on regular review in hospital out-patient clinics for a period of between five to 10 years after completion of their treatment. The aims may be to detect recurrence of tumour, to monitor late effects of treatment, to collect data and to offer patients an opportunity to raise concerns or anxieties arising from their cancer. The assumption behind this approach is that early detection of recurrence will be of benefit to ~~the~~ patients and that monitoring side-effects and anxieties will allow helpful interventions that will improve ~~the patient's~~ quality of life.

Routine follow-up is a time-consuming and expensive process with many hundreds of patients attending clinics in each hospital each year at an NHS tariff of £118 per visit (Department of Health, 2011). In Wales alone we estimate the cost of this follow up is in excess of £1m annually. If the object is the early detection of recurrent disease, studies investigating recurrence for breast cancer reported most recurrences presenting between scheduled clinic appointments (Brøyn and Frøyen, 1982; Grunfeld *et al*, 1996; Pandya *et al*, 1985; Scanlon *et al*, 1980; Winchester *et al*, 1979; Zwaveling *et al*, 1987) and gynaecological patients may wait for their next routine appointment to disclose their symptoms (Olaitan *et al*, 2001). There is no prospective randomised evidence to suggest follow-up improves survival for ovarian cancer and retrospective data only to guide follow-up strategies for cervical cancer (Kew *et al,* 2011; Elit *et al,* 2009). Also there is no evidence that intensive follow up improves survival for endometrial cancer (Agboola *et al,* 1997; Allsop *et al,* 1997; Gadducci *et al,* 2000; Owen and Duncan, 1996; Reddoch *et al,* 1995; Salvesen *et al,* 1997; Shumsky *et al,* 1994). A cost benefit analysis for endometrial carcinoma showed that one asymptomatic recurrence was detected in every 653 consultations (Salvesen *et al*, 1997). In a review of 12 studies, only 30% of endometrial cancer recurrences were asymptomatic and methods of follow-up were unrelated to survival (Fung-Kee-Fung *et al,* 2006). As around 20% of all female cancer survivors have had gynaecological malignancy a cost effective form of surveillance is important (Salani *et al,* 2011).

In clinical practice there appears to be no rationale available for any particular follow-up protocol (Sartori *et al,* 2010). Rapid access to oncological assessment at recurrence may be more important than offering frequent routine appointments. Given that patients wish to be cured of their disease and that different schedules of follow-up do not appear to have an impact upon survival, delegation of routine follow-up could be to other carers. Telephone consultations can free oncologists' clinic time and is convenient for patients. Follow-up may be in primary care, a hospital based nurse led clinic, by telephone or at the request of the patient. Despite its place in standard healthcare the benefits of routine follow-up following treatment for gynaecological cancer has received little scrutiny and has rarely been subjected to formal assessment.

In order to determine a baseline of current practice for gynaecological cancer follow-up in the United Kingdom, we have performed a survey of cancer follow-up in gynaecological oncology. The intention ~~aim~~ is to investigate who performs follow-up, for what duration and how this is achieved to see if there is a possibility to improve the quality of care offered to patients after their cancer treatment.

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Materials and methods

The follow-up survey was designed using the Bristol Online Survey (BOS) to provide electronic data capture and data management support to the questionnaire. The BOS is an easy-to-use survey tool, which allows developing, deploying and analysing surveys via the internet. The dataset was managed by the Information Systems Department at the North Wales Organisation of Randomised Trials (Bangor University). Data was anonymised and then exported to the databases held in SPSS ™ (version 18.0; SPSS, Chicago, IL). The e-survey targeted gynaecological cancer secondary care practitioners~~experts~~ (incorporating surgical and non-surgical specialists) in all cancer networks in the United Kingdom. It was available online using an electronic web link from June to September 2012. An initial invitation email and a reminder with the web link were sent through the Principal Investigator (PI) distribution list to all 401 members of the British Gynaecological Cancer Society (BGCS) and all 71 members of the National Forum of Gynaecological Oncology Nurses (NFGON). A news release published in June 2012 on the BGCS website also invited members to take part in the survey. It is possible that respondents could provide multiple replies but no two responses from the same network were identical.

The investigators in consultation with the BGCS and a patient representative designed the questionnaire which was organised around three themes (see questionnaire in appendix). The first comprised questions related to practice setting (i.e. organisation and hospital) and respondent characteristics (i.e. profession and medical specialty). The second comprised questions related to the use of standard protocols for follow-up. The bulk of the questionnaire addressed information about the different schedules of follow-up and which surveillance tests were used routinely in follow-up practices for different type of cancers. We listed four possible types of follow-up appointments; clinician led (traditional), nurse led, telephone follow-up and patient initiated follow-up. Telephone follow-up appointments were defined as a pre-arrangement for a member of the cancer team to contact the patient by telephone without a need for the patient to attend hospital. Patient initiated follow-up was defined as practice where the patient is not followed-up in secondary care but seen only if the patient requests or initiates a contact, for example if they are worried about a suspicion of recurrent disease.

Most answers were recorded as a binary variable (yes/no answer) with additional, open text box response options throughout the questionnaire for comments and alternative suggestions.

Data was collated and presented as numbers and a percentage of positive responses. For those questions composed of a subset of questions, the number of positive responses in the main question was used as the denominator for the subset.~~applicable denominators.~~ The geographical spread of responses was mapped. Textual answers were categorised and counted.

Results

Sample size and respondents characteristics

Responses were received from 118 experts in gynaecological cancer drawn from the membership of the BGCS and NFGON. Because the survey was conducted online with the request to take part distributed widely by email it is impossible to state how many had the opportunity to take part but did not. Therefore the response rate has not been calculated. Nonetheless we received responses from 86% (24/28) of the cancer networks in England and all cancer networks in Scotland (three), Wales (two), ~~Scotland (three)~~ and Northern Ireland (one). Each responding cancer network provided between one to 14 responses. One response was received from a surgical oncologist based in Greece who has been excluded from the study as the objective is assessing current practice of follow-up after gynaecological cancer treatment in the UK. Of the 117 respondents~~cancer specialists~~ included in the study, 71 (61%) worked in a cancer centre, 32 (27%) in a cancer unit and 12 (10%) reported working in both. Eighty-eight (75%) of the respondents were surgical oncologists. Fifteen (13%) were clinical oncologists and six (5%) were specialised in medical oncology. The majority of the respondents (83 (71%)) were doctors while nurses constituted less than a third of the sample (32 (27%)). Full results are presented in table 1.

Standard follow-up protocols

All respondents with the exception of one surgical oncologist (116/117 (99%)) ~~reported that they~~ had a standard follow-up protocol after completion of treatment. However all 30 networks providing responses had at least one respondent reporting having protocols for follow-up. The vast majority of respondents provided follow-up in secondary care, only two respondents (from different English cancer networks) reported that visits to primary care are part of their follow-up routine.

Most 87/116 (75%) of the respondents reported using different follow-up protocols for different tumour sites (eg. cervix and ovary) and 35/116 (30%) reported having ~~a~~ different protocols for different tumour types (eg. well or poorly differentiated). On a cancer network basis, different ~~identical~~ protocols for different tumour sites were reported from~~in~~ 29~~16~~/30 (97%) networks. Different~~Identical~~ protocols for different tumour types were reported by respondents from 17~~2~~/30 (57%)~~3 of the 24 English~~ networks~~, both of the Wales networks, the Northern Ireland network, and one of the cancer networks in Scotland~~.

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Composition follow-up appointments

All respondents in our sample reported they follow-up patients after completion of gynaecological cancer treatment. One hundred and fifteen (98%) reported hospital scheduled regular follow-up appointments from which the patient may be discharged if she remains disease free after a specified period of time. This follow-up was augmented or replaced by a telephone follow-up in 29 (25%) and patient initiated appointments in 38 responses (32%). A combination of all three forms of follow-up was reported by 11 respondents (a total of 54 respondents offered more than one modality of follow-up). ~~regular, telephone or patient initiated follow-up was available from 33 respondents and~~ O~~o~~f these 1~~89~~/54 (33%) ~~(58%)~~ reported that patients have an opportunity to~~could~~ attend either a medical or a nurse led clinic. However, 6/1~~89~~ (3~~32~~%) did not have a protocol to allocate patients to each clinic. For patient initiated appointments, 10/38 (26%) ~~of the specialists~~ did not have a protocol with contact

details (eg. a secretary, Macmillan nurse or General Practitioner) for self-referrals. A total of 80~~8~~/117 (68%) cancer specialists from 27/30 networks (90%) also offered combined follow-up clinics with other specialties (eg. combined surgical and medical oncology or surgical and clinical oncology clinics).

Virtually all respondents reported in the case of sudden events that symptomatic patients could arrange an appointment in less than two weeks. Seven (6%) respondents from five different cancer networks answered that their practices schedule urgent appointments in a period of two to four weeks, from which two of them also scheduled urgent patient initiated appointments in the same timeframe.

Follow-up in hospital wa~~i~~s mainly performed by doctors (67% for scheduled regular appointments and 63% for patient initiated appointments) while telephone follow-up care wa~~i~~s provided in its majority by nurses (76%). Full details are illustrated in table 2.

Duration of follow-up and surveillance tests

The survey asked respondents whether they perform any type of routine ~~follow-up or~~ surveillance test during follow-up. Routine tests were~~are~~ requested~~provided~~ by 65% (76/117) of respondents, from which 87% (66/76) requested~~reported carrying out~~ tests for ovarian cancer, 46% (35/76) for cervical cancer, 11% (8/76) for vulva cancer and nine per cent (7/76) for endometrial cancer. In addition, respondents were asked to provide details of when these tests are performed but only a few responses were obtained. Table 3 shows the distribution of the different type of tests employed during follow-up.

CA125 measurement was the most frequently used test (60/66 (91%)) during follow-up of ovarian cancer patients. O~~followed by o~~ther blood tests (8/66 (12%)), eg. alpha-fetoprotein , carcino-embryonic antigen , CA19.9 and inihibin were also requested. The routine use of computed tomography and magnetic resonance imaging (MRI) scans for ovarian cancer were reported by 9/66 (14%) of the respondents (one respondent used both CT and MRI). Eight respondents~~cancer specialists~~ stated the CA125 test is performed at each visit. Another seven ~~specialists~~ reported the CA125 is performed every three months for the first year after completion of treatment, from which two ~~of them~~ reported they carry on with routine testing for the second year and four up to the fifth year ~~five~~ every six months.

The use of MRI (15/35 (43%)) was the most common investigation employed in the follow-up of cervical cancer with cervical or vaginal cytology being the second commonest method (14/35 (40%)). There was a wide variety of tests (8/35 (23%)) reported in the follow-up of this type of cancer. Two of the respondents stated they perform vault cytology for cervical cancer patients annually for a period of five years following hysterectomy, while three specialists reported carrying out the test at six and 18 months post-treatment.

Most respondents discharged their patients after five years of follow-up (82/117 (70%)), three (3%) after four years, nine (8%) after three and one (1%) after two years whereas 22/117 (19%) of respondents did not answer this question.

Discussion

The current survey is the first evidence reporting the extent of patient initiated, specialist nurse or telephone follow-up for gynaecological cancer in the UK. There were no respondents for four cancer networks and because the survey was online, a response rate could not be calculated. This could introduce a potential source of bias if the answers from respondents were not representative of their relevant professional communities. Different protocols for different tumour sites and types and the use of combined speciality follow-up clinics were more often reported from network responses than for individual responses because network responses included respondents with at least one positive response in each network. Unfortunately we could not calculate the agreement level within networks because of the small numbers of respondents from each network. The lack of consistency of responses within networks is again a potential source of error. Our survey ~~also~~ shows that all gynaecological cancer networks providing responses have protocols for follow-up after treatment. Follow-up for patients treated for gynaecological cancer is mainly performed by doctors in secondary care. Patient initiated follow-up was offered by 32% of respondents and telephone follow-up was offered by 25%. A large minority of patient initiated follow-up and combined follow-up schedules did not have protocols to guide practice. The most common duration of routine follow-up wa~~i~~s for five years. There are few routine tests undertaken during follow-up to detect recurrence and they show no consistency particularly for cervical cancer. Of the 35 respondents who requested tests for cervical cancer follow-up, 15 (43%) requested MRI and 14 (40%) requested cytology. Such variation is not surprising with the lack of evidence to guide clinical management. The exception is CA125 testing following treatment for ovarian cancer where 52% of all respondents recommended CA125 monitoring despite grade one evidence to demonstrate that routine CA125 measurements do not benefit asymptomatic patients having had ovarian cancer (Rustin *et al,* 2010). Furthermore, there appears to have been no recent change of this practice in our survey, as monitoring with CA125 testing was reported in 24 of the 34 UK networks (71%) whereas 67% of networks recommended such testing in an earlier survey (Kew and Cruickshank, 2006). Respondents were asked not to include tests requested during treatment but tests could have been included as part of trial protocols. ~~Patient initiated follow-up was offered by 32% of respondents and telephone follow-up was offered by 25%. A large minority of patient initiated follow-up and combined follow-up schedules did not have protocols to guide practice. The most common duration of routine follow-up is for five years.~~

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Vistad *et al* (2012) also published results of a web-based survey of practice amongst gynaecological oncologists across Europe and reported that 47% of the 375 respondents considered follow-up with General Practitioners to be acceptable. Other options for care were not considered and the response rate was thought to be below 20%. However there appears to be little or no evidence upon which to guide follow-up for gynaecological malignancy from the survey by Vistad *et al,* the earlier survey from the UK (Kew and Cruickshank, 2006) and from our work.

From other research, patients with previous ovarian cancer rated CA125 testing as the most important part of follow-up (Kew *et al,* 2009) despite a lack of evidence of benefit from routine measurement of~~despite the knowledge that routinely measuring~~ the CA125 value upon~~does not improve~~ survival (Rustin *et al,* 2010). Furthermore knowledge of recurrence whether treatable or not appears useful to patients (Papagrigoriadis and Heyman, 2003) ~~(Kew *et al,* 2009)~~ and information should be provided to detail the scope and limitations of follow-up (Kew *et al,* 2007). Rapid access to oncological assessment at recurrence may be more important than offering frequent routine appointments. Given that

patients wish to be cured of their disease and knowing that different schedules of follow-up do not have an impact upon survival, delegation of routine follow-up could be to other carers (Vistad *et al,* 2012). Follow-up may be in primary care, a hospital based nurse led clinic, by telephone or at the request of the patient. An individualised approach to follow-up is likely to be important to concentrate care for those perceived to be at a greater risk of recurrent disease or other issues of survivorship. This may include a risk stratification~~assessment~~ where there are effective interventions for physical, psychological and social issues as well as needs assessments which are clearly patient centred as defined by the National Cancer Survivorship Initiative (Watson *et al,* 2012) whilst bearing in mind that a minority of patients may be cured with further therapy. Follow-up has to be multidisciplinary, designed for risk of recurrence and with good communication between professional groups. Informed patient choice regarding mode and frequency of follow-up is important. Reducing the frequency of follow-up appointments may not place an increased demand upon unnecessary patient initiated extra hospital appointments and patients may prefer fewer appointments (Gulliford *et al,* 1997). The ideal time of advising a patient about a preferred form of follow-up is unclear but may be shortly after all modalities of treatment have been completed.

Healthcare providers should be informed by prospective data on the validity of alternative strategies for gynaecological cancer follow-up which is already a minority part of current UK practice. The North Wales Organisation for Randomised Trials in Health in collaboration with several leading gynaecological oncologists has previously developed a proposal for a randomised study to assess the value of hospital follow-up of endometrial cancer (Follow-up in Gynaecological Cancer Units: RCT for Endometrium or FIGURE). The proposal was for a multicentre, randomised trial comparing standard (hospital) follow-up with patient initiated review. The endpoints were to be quality of life and survival with a planned recruitment of 2200 patients to detect an effect size of 0.2. Unfortunately, although the proposal was well received, it was impossible to agree a level of funding to allow the study to proceed. More recently the Endometrial Cancer Telephone Follow-up Trial (ENDCAT ISRCTN 75220876) has started. This is a study comparing traditional hospital follow-up with telephone follow-up by specialist gynaecology oncology nurses with primary outcomes of psychological morbidity and patient satisfaction. Again this is a randomised trial for endometrial cancers only and is at a single centre. It is currently recruiting to schedule and is due to close in 2014. A Trial between Two Follow-up Regimens with Different Intensity in Endometrial Cancer Treated Patients (TOTEM NCT00916708) is a further ongoing but multicentre randomised trial in Italy, comparing overall survival, progression free survival, complications, proportion of asymptomatic relapse and the proportion of patients completing each regimen for follow-up. It is due to close in 2015.

Our study has demonstrated that the vast majority of follow-up still reflects traditional patterns, with only about a third of practitioners incorporating more flexible follow-up routines. However, the evidence base for changing practice to a less intensive follow-up programme for gynaecological cancer is poor and Vistad *et al* (2011) reported no randomised studies on this subject. A~~Current trial activity suggests a~~ trial similar to FIGURE should be revisited but to include follow-up for more than one gynaecological cancer site. ~~Practice has already begun to change to include patient initiated follow-up for gynaecological cancer patients but our survey has demonstrated that these changes are not yet widespread. However, the evidence base for changing practice to a less intensive follow-up programme for gynaecological cancer is poor and Vistad *et al* (2011) reported no randomised studies on this subject. The current scoping study has demonstrated that the vast majority of follow-up still reflects traditional patterns, with only about a third of practitioners incorporating more flexible follow-~~

~~up routines into their practice.~~ In the~~our~~ present~~current~~ constrained financial environment, to continue to use patterns of follow-up for gynaecological cancers which are neither evidence-based nor affordable is inappropriate. ~~We aim to develop a suite of pilot and feasibility studies that may lead to a UK~~ A multicentre randomised controlled trial could ~~to~~ assess the clinical benefits and costs of routine hospital follow-up in comparison with the patient being empowered to choose her preferred format of follow-up for most gynaecological cancers. ~~This would incorporate information with contact details and about the possible symptoms of recurrence, with formal review only as and when required by the patient.~~ The current survey may inform design of such a trial by providing data from the UK ~~is the first in this series~~ concerning~~in assessing current~~ national practice.

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Authors' roles

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Nick Stuart	draft script development, design of questionnaire
Yvonne Sylvestre	review of data
Liz Hall	draft script development
Rhiannon Whitaker	draft script development, review of data, design of questionnaire

Table 1: Characteristics of respondents (N=117)

	N (%)
Region	
England	102 (87%)
Wales	7 (6%)
Scotland	5 (4%)
Northern Ireland	3 (3%)
Organisation	
Cancer centre	71 (61%)
Cancer unit	32 (27%)
Cancer unit & cancer centre	12 (10%)
Other[1]	2 (2%)
Specialty	
Surgical oncology	73 (62%)
Medical oncology	6 (5%)
Clinical oncology	15 (13%)
Surgical & medical oncology	6 (5%)
Surgical & clinical oncology	1 (1%)
Surgical, medical & clinical oncology	8 (7%)
Other[2]	8 (7%)
Profession	
Medical	83 (71%)
Nursing	32 (27%)
Other[3]	2 (2%)

1. Includes gynaecology unit in a chemotherapy centre (n=1) and hospital (n=1).
2. Includes clinical nurse specialist (n=2), nursing (n=2), gynaecology (n=2), gynaecology & surgical oncology (n=1) and pathology (n=1).
3. Includes consultant radiographer (n=1) and missing response (n=1).

Table 2: Type and frequency of occurrence of differing modes of follow-up

	Regular	Telephone	Patient initiated
Positive responses	115/117 (98%)	29/117 (25%)	38/117 (32%)
Urgent follow-up bookings			
< 2 weeks	108/115 (94%)	29/29 (100%)	35/38 (92%)
2 to 4 weeks	7/115 (6%)	0 (0%)	2/38 (5%)
Responsible for follow-up			
Doctors	77/115 (67%)	4/29 (14%)	24/38 (63%)
Nurses	0 (0%)	22/29 (76%)	2/38 (5%)
Doctors & nurses	36/115 (31%)	3/29 (10%)	11/38 (29%)
Other[1]	2/115 (2%)	1/29 (3%)	1/38 (3%)

1. Includes radiographer (n=1), consultant radiographer (n=1), for regular appointments; specialist radiographer (n=1) for telephone appointments and missing response (n=1) for patient initiated appointments.

Table 3: Frequency of surveillance tests reported by type of test and cancer type

	Ultrasound†	CA125	Other blood tests*	CT	MRI	Cytology	Other¶	Total
Ovarian	5	60	8	5	4	0	0	82
Cervical	1	0	4	0	15	14	3	37
Endometrial	1	1	0	0	1	1	0	4
Vulval	0	0	0	0	1	0	4	5

Key: CA125, cancer antigen 125; CT, computed tomography; MRI, magnetic resonance imaging.
† Ultrasound includes: abdominal and transvaginal ultrasound.
** Other blood tests includes: other tumour markers (n=8) for ovarian cancer and squamous cancer antigen (n=3) for cervical cancer.*
¶ Other includes: colposcopy (n=2) for cervical cancer and vulvoscopy (n=3) for vulval cancer.

Appendix: Gynaecological cancer follow-up survey of current practice

Introduction

Patients may appreciate the attention given to follow up after treatment for cancer yet the survival benefit of follow up is unclear. We are planning to review local practice to determine if follow up to detect recurrence at an early stage can improve survival. However a preliminary assessment of national practice would be ideal. A prospective study of follow up strategies may follow. We would appreciate a few minutes of your time as cancer specialists to complete the following questionnaire.

Questions

Q1. In which cancer network do you work?

Q2. Where do you work?

i. Cancer Centre
ii. Cancer unit
iii. Other (please specify)

Q3.Please enter name of the hospital (s)at which you work? (Optional)

Q4. Is your work within surgical, medical or clinical oncology or another discipline?

i. Surgical oncology
ii. Medical oncology
iii. Clinical oncology
iv. Imaging
v. Pathology
iv. Other (please specify)

Q4.a. What is your profession?

i. Medical
ii. Nursing
iii. Other (please specify)

Q5. Do you have a standard follow up protocol following completion of treatment for gynaecological cancer?

i. Yes
ii. No
iii. Don't know

Q5a. Do you have a different protocol for different tumour sites e.g. cervix and ovary?

i. Yes
ii. No
iii. Don't know

Q5b. Do you have a different protocol for different tumour types e.g. well or poorly differentiated?

i. Yes
ii. No
iii. Don't know

Q5c. Does the routine follow-up involve visits to primary care?

i. Yes
ii. No
iii. Don't know

Q6. Do you have regular follow-up appointments? Regular follow-up appointments here means an agreed schedule of visits from which the patient may discharge if she remains disease free after a specified period of time.

i. Yes
ii. No
iii. Don't know

Q6a. If so, when can you book urgent follow-up appointments for symptomatic patients?

i. In less than 2 weeks
ii. 2-4
iii. 4+ weeks
iv. Don't know

Q6b. Who provides the follow-up?

i. Nurses
ii. Doctors
iii. Don't know
iv. Other (please specify)

Q7. Do you have telephone follow-up appointments? A telephone follow-up appointment is an appointment pre-arranged for a member of the cancer team to contact the patient by telephone without a need for the patient to attend hospital.

i. Yes
ii. No
iii. Don't know

Q7a. If so when can you book urgent follow-up appointments for symptomatic patients?

i. In less than 2 weeks
ii. 2-4
iii. 4+ weeks
iv. Don't know

Q7b. Who provides the follow-up?

i. Nurses
ii. Doctors
iii. Don't know
iv. Other (please specify)

Q8. Do you have patient initiated follow-up appointments? Patient initiated follow-up is when the patent is not followed-up in secondary care but sees only if the patent requests (such as suspicion of recurrent disease).

i. Yes
ii. No
iii. Don't know

Q8a. Do you have a protocol for asking patients to self-refer with contact details (e.g. a secretary, Macmillan Nurse or her GP)?

i. Yes
ii. No
iii. Don't know

Q8b. If so, can urgent appointments for symptomatic patients be booked? To see the patient

i. In less than 2 weeks
ii. 2-4
iii. 4+ weeks
iv. Don't know

Q8c. Who provides the follow-up?

i. Nurses
ii. Doctors
iii. Don't know
iv. Other (please specify)

Q9. Do you have a combination of regular follow-up, telephone follow up and/ or patient initiated follow-up appointments?

i. Yes
ii. No
iii. Don't know

Q9a. Do you have a follow-up where patients attend either a medical or a nurse led clinic?

i. Yes
ii. No
iii. Don't know

Q9b. If yes, do you have a protocol to allocate patents to each clinic?

i. Yes
ii. No

Q10. Do you have combined follow-up clinics with other specialties (e.g. combined surgical and medical oncology, surgical and clinical oncology clinics?

i. Yes
ii. No
iii. Don't know

Q10a. If yes please specify

i. Clinical
ii. Medical
iii. Surgical oncology

Q11. During follow-up do you carry out certain blood tests (e.g. CA125), vault cytology or imaging such as CT or MR routinely for cases at a certain time interval?

i. Yes
ii. No
iii. Don't know

Q11a. Ovary

i. Yes
ii. No

Q11a.i. Please provide details of which tests and when these are usually carried if possible

Q11b. Cervix

i. Yes
ii. No

Q11b.i. Please provide details of which tests and when these are usually carried if possible

Q11c. Endometrium

i. Yes
ii. No

Q11c.i. Please provide details of which tests and when these are usually carried if possible

Q11d. Vulva

i. Yes
ii. No

Q11d.i. Please provide details of which tests and when these are usually carried if possible

Q11e. Other

i. Yes
ii. No

Q11e.i. Please provide details of which tumour site(s)

Q11e.i.i. Please provide details of which tests and when these are usually carried if possible

Q12. After how many years of follow up are patients usually discharged?

i. 1
ii. 2
iii. 3
iv. 4
v. 5
vi. 6
vii. 7
viii. 8
ix. 9
x. 10
xi. 10+
xii. Never
xiii. N/A
xiv. Other(please specify)

Q13. If we were to develop a larger study would your centre be prepared to participate?

i. Yes
ii. No

Q13a. If so please add contact details here or email Simon Leeson

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Gynaecological cancer follow-up: National survey of current practice in the UK

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Gynaecological cancer follow-up national survey of current practice

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Key words: neoplasm, questionnaires, female continuity of patient care/standards, survivorship, neoplasm recurrence

Abstract

Objective
To establish a baseline of national practice for follow-up after treatment for gynaecological cancer.

Design
Questionnaire survey.

Setting
Gynaecological cancer centres and units.

Geographical location
UK

Participants
Members of the British Gynaecological Cancer Society and the National Forum of Gynaecological Oncology Nurses**.**

Interventions
A questionnaire survey.

Outcome measures
To determine schedules of follow-up, who provides it and what routine testing is used for patients who have had previous gynaecological cancer.

Results
A total of 117 responses were obtained; 115 (98%) reported hospital scheduled regular follow-up appointments. Two involved General Practitioners. Follow-up was augmented or replaced by telephone follow-up in 29 (25%) and patient initiated appointments in 38 responses (32%). A total of 80 (68%) cancer specialists also offered combined follow-up clinics with other specialties. Clinical examinations for hospital based follow-up were mainly performed by doctors (67% for scheduled regular appointments and 63% for patient initiated appointments) while telephone follow-up was provided in the majority by nurses (76%). Most respondents provided routine tests (76/117 (65%)), from which 66/76 (87%) reported carrying out surveillance tests for ovarian cancer, 35/76 (46%) for cervical cancer, 8/76 (11%) for vulval cancer and 7/76 (9%) for endometrial cancer. Usually patients were discharged after five years (82/117 (70%)), whereas three (3%) were discharged after four years, nine (8%) after three and one (1%) after two years.

Conclusions
Practice varied but most used a standard hospital based protocol of appointments for five years and routine tests were performed usually for women with ovarian cancer. A minority utilised nurse led or telephone follow-up. General Practitioners were rarely involved in routine care. A randomised study comparing various models of follow-up could be considered.

273 words

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Article summary

Article focus

- Follow-up after treatment for cancer is a resource intense area of clinical practice which does not have clear benefits for patients.
- Doctors and nurses involved in care for women with gynaecological cancer were invited to respond to a questionnaire survey.
- A survey is presented of current follow-up after treatment for gynaecological cancer in the UK.

Key messages

- There is a variation of follow-up practice throughout the UK.
- A minority used nurse led or telephone follow-up as opposed to a conventional series of hospital outpatient appointments to see a doctor.

Strengths and limitations of this study

- A strength is that this is the first study to report the extent of patient initiated, specialist nurse or telephone follow-up for gynaecological cancer in the UK.
- Limitations are that four UK cancer networks did not respond, there were variations of responses within networks and the response rate could not be calculated.

Data sharing statement

The raw data has been archived at NWORTH Clinical Trials Unit and will be available to interested researchers by agreement with the Principal Investigator.

Introduction

Traditionally, patients who have had treatment for cancer are kept on regular review in hospital out-patient clinics for a period of between five to 10 years after completion of their treatment (Kew and Cruickshank, 2006). The aims may be to detect recurrence of tumour, to monitor late effects of treatment, to collect data and to offer patients an opportunity to raise concerns or anxieties arising from their cancer (Kerr-Wilson and McCrum, 1995; Kew *et al,* 2007; Kew *et al,* 2011). The assumption behind this approach is that early detection of recurrence will be of benefit to patients (Lajer *et al,* 2012; Vistad *et al,* 2012) and that monitoring side-effects and anxieties will allow helpful interventions that will improve quality of life.

Routine follow-up is a time-consuming and expensive process with many hundreds of patients attending clinics in each hospital each year at an NHS tariff of £118 per visit (Department of Health, 2011). In Wales alone we estimate the cost of this follow up is in excess of £1m annually. If the object is the early detection of recurrent disease, studies investigating recurrence for breast cancer reported most recurrences presenting between scheduled clinic appointments (Brøyn and Frøyen, 1982; Grunfeld *et al*, 1996; Pandya *et al*, 1985; Scanlon *et al*, 1980; Winchester *et al*, 1979; Zwaveling *et al*, 1987). This is also seen with patients having had treatment for early stage endometrial and cervical cancers (Shumsky *et al,* 1994; Vistad *et al,* 2011). Gynaecological patients may wait for their next routine appointment to disclose their symptoms (Olaitan *et al*, 2001). There is no prospective randomised evidence to suggest follow-up improves survival for ovarian cancer (Kew *et al,* 2011) or for cervical cancer (Elit *et al,* 2009). Also there is no evidence that intensive follow up improves survival for endometrial cancer (Agboola *et al,* 1997; Allsop *et al,* 1997; Gadducci *et al,* 2000; Owen and Duncan, 1996; Reddoch *et al,* 1995; Salvesen *et al,* 1997; Shumsky *et al,* 1994). A cost benefit analysis for endometrial carcinoma showed that one asymptomatic recurrence was detected in every 653 consultations (Salvesen *et al*, 1997). In a review of 12 studies, only 30% of endometrial cancer recurrences were asymptomatic and methods of follow-up were unrelated to survival (Fung-Kee-Fung *et al,* 2006). As around 20% of all female cancer survivors have had gynaecological malignancy a cost effective form of surveillance is important (Salani *et al,* 2011).

In clinical practice there appears to be no rationale available for any particular follow-up protocol (Sartori *et al,* 2010). As there is a lack of any demonstrable survival benefit for the follow-up of gynaecological cancer patients, other schedules of care could be considered. Telephone consultations can free oncologists' clinic time and is convenient for patients. Follow-up may be in primary care, a hospital based nurse led clinic, by telephone or at the request of the patient. Despite its place in standard healthcare the benefits of routine follow-up following treatment for gynaecological cancer has received little scrutiny and has rarely been subjected to formal assessment.

In order to determine a baseline of current practice for gynaecological cancer follow-up in the United Kingdom, we have performed a survey of cancer follow-up in gynaecological oncology. The intention is to investigate who performs follow-up, for what duration and how this is achieved to see if there is a possibility to improve the quality of care offered to patients after their cancer treatment.

Materials and methods

The follow-up survey was designed using the Bristol Online Survey (BOS) to provide electronic data capture and data management support to the questionnaire. The BOS is an easy-to-use survey tool, which allows developing, deploying and analysing surveys via the internet. The dataset was managed by the Information Systems Department at the North Wales Organisation of Randomised Trials (Bangor University). Data was anonymised and then exported to the databases held in SPSS ™ (version 18.0; SPSS, Chicago, IL). The e-survey targeted gynaecological cancer secondary care practitioners (incorporating surgical and non-surgical specialists) in all cancer networks in the United Kingdom. It was available online using an electronic web link from June to September 2012. An initial invitation email and a reminder with the web link were sent through the Principal Investigator (PI) distribution list to all 441 members of the British Gynaecological Cancer Society (BGCS) and all 71 members of the National Forum of Gynaecological Oncology Nurses (NFGON). A news release published in June 2012 on the BGCS website also invited members to take part in the survey. It is possible that respondents could provide multiple replies but no two responses from the same network were identical.

The investigators in consultation with the BGCS and a patient representative designed the questionnaire which was organised around three themes (see questionnaire in appendix). The first comprised questions related to practice setting (i.e. organisation and hospital) and respondent characteristics (i.e. profession and medical specialty). The second comprised questions related to the use of standard protocols for follow-up. The bulk of the questionnaire addressed information about the different schedules of follow-up and which surveillance tests were used routinely in follow-up practices for different cancers. We listed four possible types of follow-up appointments; clinician led (traditional), nurse led, telephone follow-up and patient initiated follow-up. Telephone follow-up appointments were defined as a pre-arrangement for a member of the cancer team to contact the patient by telephone without a need for the patient to attend hospital. Patient initiated follow-up was defined as practice where the patient is not followed-up in secondary care but seen only if the patient requests or initiates a contact, for example if they are worried about a suspicion of recurrent disease.

Most answers were recorded as a binary variable (yes/no answer) with additional, open text box response options throughout the questionnaire for comments and alternative suggestions.

Data was collated and presented as numbers and a percentage of positive responses. For those questions composed of a subset of questions, the number of positive responses in the main question was used as the denominator for the subset. The geographical spread of responses was mapped by calculating responses also on a network basis, grouping all answers from respondents within their cancer networks. Any positive response within the group was accepted as a positive network response. Textual answers were categorised and counted.

Results

Sample size and respondents characteristics

Responses were received from 118 experts in gynaecological cancer drawn from the membership of the BGCS and NFGON. Because the survey was conducted online with the request to take part distributed widely by email it is impossible to state how many had the opportunity to take part but did not. Therefore the response rate has not been calculated. Nonetheless we received responses from 86% (24/28) of the cancer networks in England and all cancer networks in Scotland (three), Wales (two), and Northern Ireland (one). Each responding cancer network provided between one to 14 responses. One response was received from a surgical oncologist based in Greece who has been excluded from the study as the objective is assessing current practice of follow-up after gynaecological cancer treatment in the UK. Of the 117 respondents included in the study, 71 (61%) worked in a cancer centre, 32 (27%) in a cancer unit and 12 (10%) reported working in both. Eighty-eight (75%) of the respondents specialised in surgical oncology. Fifteen (13%) specialised in clinical oncology and six (5%) in medical oncology. The majority of the respondents (83 (71%)) were doctors while nurses constituted less than a third of the sample (32 (27%)). Full results are presented in table 1.

Standard follow-up protocols

All respondents with the exception of one surgical oncologist (116/117 (99%)) had a standard follow-up protocol after completion of treatment. However all 30 networks providing responses had at least one respondent reporting having protocols for follow-up. The vast majority of respondents provided follow-up in secondary care, only two respondents (from different English cancer networks) reported that visits to primary care are part of their follow-up routine.

Most 87/116 (75%) of the respondents reported using different follow-up protocols for different tumour sites (eg. cervix and ovary) and 35/116 (30%) reported having different protocols for different tumour types (eg. well or poorly differentiated). On a cancer network basis, different protocols for different tumour sites were reported from 29/30 (97%) networks. Different protocols for different tumour types were reported by respondents from 17/30 (57%) networks.

Composition follow-up appointments

All respondents in our sample reported they follow-up patients after completion of gynaecological cancer treatment. One hundred and fifteen (98%) reported hospital scheduled regular follow-up appointments from which the patient may be discharged if she remains disease free after a specified period of time. This follow-up was augmented or replaced by a telephone follow-up in 29 (25%) and patient initiated appointments in 38 responses (32%). A combination of all three forms of follow-up was reported by 11 respondents (a total of 54 respondents offered more than one modality of follow-up). Of these 18/54 (33%) reported that patients have an opportunity to attend either a medical or a nurse led clinic. However, 6/18 (33%) did not have a protocol to allocate patients to each clinic. For patient initiated appointments, 10/38 (26%) did not have a protocol with contact details (eg. a secretary, Macmillan nurse or General Practitioner) for self-referrals. A total of 80/117 (68%) cancer specialists from 27/30 networks (90%) also offered combined follow-up clinics with other specialties (eg. combined surgical and medical oncology or surgical and clinical oncology clinics).

Virtually all respondents reported in the case of sudden events that symptomatic patients could arrange an appointment in less than two weeks. Seven (6%) respondents from five different cancer networks answered that their practices schedule urgent appointments in a period of two to four weeks, from which two of them also scheduled urgent patient initiated appointments in the same timeframe.

Follow-up in hospital was mainly performed by doctors (67% for scheduled regular appointments and 63% for patient initiated appointments) while telephone follow-up care was provided in its majority by nurses (76%). Full details are illustrated in table 2.

Duration of follow-up and surveillance tests

The survey asked respondents whether they perform any type of routine surveillance test during follow-up. Routine tests were requested by 65% (76/117) of respondents, from which 87% (66/76) requested tests for ovarian cancer, 46% (35/76) for cervical cancer, 11% (8/76) for vulva cancer and nine per cent (7/76) for endometrial cancer. In addition, respondents were asked to provide details of when these tests are performed but only a few responses were obtained. Table 3 shows the distribution of the different type of tests employed during follow-up.

CA125 measurement was the most frequently used test (60/66 (91%)) during follow-up of ovarian cancer patients. Other blood tests (8/66 (12%)), e.g. alpha-fetoprotein , carcino-embryonic antigen , CA19.9 and inihibin were also requested. The routine use of computed tomography and magnetic resonance imaging (MRI) scans for ovarian cancer were reported by 9/66 (14%) of the respondents (one respondent used both CT and MRI). Eight respondents stated the CA125 test is performed at each visit. Another seven reported the CA125 is performed every three months for the first year after completion of treatment, from which two reported they carry on with routine testing for the second year and four up to the fifth year every six months.

The use of MRI (15/35 (43%)) was the most common investigation employed in the follow-up of cervical cancer with cervical or vaginal cytology being the second commonest method (14/35 (40%)). There was a wide variety of tests (8/35 (23%)) reported in the follow-up of this type of cancer. Two of the respondents stated they perform vault cytology for cervical cancer patients annually for a period of five years following hysterectomy, while three specialists reported carrying out the test at six and 18 months post-treatment.

Most respondents discharged their patients after five years of follow-up (82/117 (70%)), three (3%) after four years, nine (8%) after three and one (1%) after two years whereas 22/117 (19%) of respondents did not answer this question.

Discussion

The current survey is the first evidence reporting the extent of patient initiated, specialist nurse or telephone follow-up for gynaecological cancer in the UK. There were no respondents for four cancer networks and because the survey was online, a response rate could not be calculated. Whilst we know

the membership of the professional societies invited to respond, we do not know whether the entire membership received or read their invitations to participate in our survey. Nonetheless a low response rate could introduce a potential source of bias if the answers from respondents were not representative of their relevant professional communities. Different protocols for different tumour sites and types and the use of combined speciality follow-up clinics were more often reported from network responses than for individual responses because positive network responses included respondents with at least one positive response in each network. Unfortunately we could not calculate the agreement level within networks because of the small numbers of respondents from each network. The lack of consistency of responses within networks is again a potential source of error as such responses may not accurately reflect local practice. We did not review the content of the follow-up protocols and so we cannot verify if these variations represent locally approved practice within each network. Network guidelines may be adapted for local use or not followed exactly, so variation within networks would be expected. Our survey shows that all gynaecological cancer networks providing responses have protocols for follow-up after treatment. Follow-up for patients treated for gynaecological cancer is mainly performed by doctors in secondary care. Patient initiated follow-up was offered by 32% of respondents and telephone follow-up was offered by 25%. A large minority of patient initiated follow-up and combined follow-up schedules did not have protocols to guide practice. The most common duration of routine follow-up was for five years. There are few routine tests undertaken during follow-up to detect recurrence and they show no consistency particularly for cervical cancer. Of the 35 respondents who requested tests for cervical cancer follow-up, 15 (43%) requested MRI and 14 (40%) requested cytology. However, cervical cytology is recommended for the follow-up of early stage cervical cancer if the cervix is conserved and was based upon expert opinion rather than upon evidence (Luesley and Leeson, 2010) Variation in the routine use of tests during follow-up is not surprising with the lack of evidence to guide clinical management. The exception is CA125 testing following treatment for ovarian cancer where 52% of all respondents recommended CA125 monitoring despite grade one evidence to demonstrate that routine CA125 measurements do not provide a survival benefit with early treatment of relapse (Rustin *et al,* 2010). Furthermore, there appears to have been no recent change of this practice in our survey, as monitoring with CA125 testing was reported in 24 of the 34 UK networks (71%) whereas 67% of networks recommended such testing in an earlier survey (Kew and Cruickshank, 2006). Respondents were asked not to include tests requested during treatment but tests could have been included as part of trial protocols. Vistad *et al* (2012) also published results of a web-based survey of practice amongst gynaecological oncologists across Europe and reported that 47% of the 375 respondents considered follow-up with General Practitioners to be acceptable. Other options for care were not considered and the response rate was thought to be below 20%.

From other research, patients with previous ovarian cancer rated CA125 testing as the most important part of follow-up (Kew *et al,* 2009). Furthermore knowledge of recurrence whether treatable or not appears useful to patients (Papagrigoriadis and Heyman, 2003) and information should be provided to detail the scope and limitations of follow-up (Kew *et al,* 2007). Rapid access to oncological assessment at recurrence may be more important than offering frequent routine appointments (Shumsky *et al,* 1994; Gulliford *et al,* 1997). Knowing that different schedules of follow-up do not have an impact upon survival, delegation of routine follow-up could be to other carers (Vistad *et al,* 2012). Follow-up may be in primary care, a hospital based nurse led clinic, by telephone or at the request of the patient. An individualised approach to follow-up is likely to be important to concentrate care for those perceived

to be at a greater risk of recurrent disease or other issues of survivorship. This may include risk stratification where there are effective interventions for physical, psychological and social issues as well as needs assessments which are clearly patient centred as defined by the National Cancer Survivorship Initiative (Watson *et al,* 2012). Follow-up has to be multidisciplinary, designed for detection of morbidity as well as recurrence and with good communication between professional groups. Informed patient choice regarding mode and frequency of follow-up is important. Reducing the frequency of follow-up appointments may not place an increased demand upon unnecessary patient initiated extra hospital appointments and patients may prefer fewer appointments (Gulliford *et al,* 1997). The ideal time of advising a patient about a preferred form of follow-up is unclear but may be shortly after all modalities of treatment have been completed.

Healthcare providers should be informed by prospective data on the validity of alternative strategies for gynaecological cancer follow-up which is already a minority part of current UK practice. The North Wales Organisation for Randomised Trials in Health in collaboration with several leading gynaecological oncologists has previously developed a proposal for a randomised study to assess the value of hospital follow-up of endometrial cancer (Follow-up in Gynaecological Cancer Units: RCT for Endometrium or FIGURE). The proposal was for a multicentre, randomised trial comparing standard (hospital) follow-up with patient initiated review. The endpoints were to be quality of life and survival with a planned recruitment of 2200 patients to detect an effect size of 0.2. Unfortunately, although the proposal was well received, it was impossible to agree a level of funding to allow the study to proceed. More recently the Endometrial Cancer Telephone Follow-up Trial (ENDCAT ISRCTN 75220876) has started. This is a study comparing traditional hospital follow-up with telephone follow-up by specialist gynaecology oncology nurses with primary outcomes of psychological morbidity and patient satisfaction. Again this is a randomised trial for endometrial cancers only and is at a single centre. It is currently recruiting to schedule and is due to close in 2014. A Trial between Two Follow-up Regimens with Different Intensity in Endometrial Cancer Treated Patients (TOTEM NCT00916708) is a further ongoing but multicentre randomised trial in Italy, comparing overall survival, progression free survival, complications, proportion of asymptomatic relapse and the proportion of patients completing each regimen for follow-up. It is due to close in 2015.

Our study has demonstrated that the vast majority of follow-up still reflects traditional patterns, with only about a third of practitioners incorporating more flexible follow-up routines. However, the evidence base for changing practice to a less intensive follow-up programme for gynaecological cancer is poor and Vistad *et al* (2011) reported no randomised studies on this subject. A trial similar to an early version of FIGURE should be revisited which included follow-up for more than one gynaecological cancer site. In the present constrained financial environment, to continue to use patterns of follow-up for gynaecological cancers which are neither evidence-based nor affordable is inappropriate. A multicentre randomised controlled trial could assess the clinical benefits and costs of routine hospital follow-up in comparison with the patient being empowered to choose her preferred format of follow-up for most gynaecological cancers. The current survey may inform design of such a trial by providing data from the UK concerning national practice.

3252 words

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Authors' roles

Simon Leeson	final manuscript preparation, review of data, design of questionnaire
Nick Stuart	draft script development, design of questionnaire
Yvonne Sylvestre	review of data
Liz Hall	draft script development
Rhiannon Whitaker	draft script development, review of data, design of questionnaire

Table 1: Characteristics of respondents (N=117)

	N (%)
Region	
England	102 (87%)
Wales	7 (6%)
Scotland	5 (4%)
Northern Ireland	3 (3%)
Organisation	
Cancer centre	71 (61%)
Cancer unit	32 (27%)
Cancer unit & cancer centre	12 (10%)
Other[1]	2 (2%)
Specialty	
Surgical oncology	73 (62%)
Medical oncology	6 (5%)
Clinical oncology	15 (13%)
Surgical & medical oncology	6 (5%)
Surgical & clinical oncology	1 (1%)
Surgical, medical & clinical oncology	8 (7%)
Other[2]	8 (7%)
Profession	
Medical	83 (71%)
Nursing	32 (27%)
Other[3]	2 (2%)

1. Includes gynaecology unit in a chemotherapy centre (n=1) and hospital (n=1).
2. Includes clinical nurse specialist (n=2), nursing (n=2), gynaecology (n=2), gynaecology & surgical oncology (n=1) and pathology (n=1).
3. Includes consultant radiographer (n=1) and missing response (n=1).

Table 2: Type and frequency of occurrence of differing modes of follow-up

	Regular	Telephone	Patient initiated
Positive responses	115/117 (98%)	29/117 (25%)	38/117 (32%)
Urgent follow-up bookings			
< 2 weeks	108/115 (94%)	29/29 (100%)	35/38 (92%)
2 to 4 weeks	7/115 (6%)	0 (0%)	2/38 (5%)
Responsible for follow-up			
Doctors	77/115 (67%)	4/29 (14%)	24/38 (63%)
Nurses	0 (0%)	22/29 (76%)	2/38 (5%)
Doctors & nurses	36/115 (31%)	3/29 (10%)	11/38 (29%)
Other[1]	2/115 (2%)	1/29 (3%)	1/38 (3%)

1. Includes radiographer (n=1), consultant radiographer (n=1), for regular appointments; specialist radiographer (n=1) for telephone appointments and missing response (n=1) for patient initiated appointments.

Table 3: Frequency of surveillance tests reported by type of test and cancer type

	Ultrasound†	CA125	Other blood tests*	CT	MRI	Cytology	Other¶	Total
Ovarian	5	60	8	5	4	0	0	82
Cervical	1	0	4	0	15	14	3	37
Endometrial	1	1	0	0	1	1	0	4
Vulval	0	0	0	0	1	0	4	5

Key: CA125, cancer antigen 125; CT, computed tomography; MRI, magnetic resonance imaging.

† Ultrasound includes: abdominal and transvaginal ultrasound.

** Other blood tests includes: other tumour markers (n=8) for ovarian cancer and squamous cancer antigen (n=3) for cervical cancer.*

¶ Other includes: colposcopy (n=2) for cervical cancer and vulvoscopy (n=3) for vulval cancer.

Gynaecological cancer follow-up national survey of current practice

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Key words: neoplasm, questionnaires, female continuity of patient care/standards, survivorship, neoplasm recurrence

Abstract

Objective
To establish a baseline of national practice for follow-up after treatment for gynaecological cancer.

Design
Questionnaire survey.

Setting
Gynaecological cancer centres and units.

Geographical location
UK

Participants
Members of the British Gynaecological Cancer Society and the National Forum of Gynaecological Oncology Nurses**.**

Interventions
A questionnaire survey.

Outcome measures
To determine schedules of follow-up, who provides it and what routine testing is used for patients who have had previous gynaecological cancer.

Results
A total of 117 responses were obtained; 115 (98%) reported hospital scheduled regular follow-up appointments. Two involved General Practitioners. Follow-up was augmented or replaced by telephone follow-up in 29 (25%) and patient initiated appointments in 38 responses (32%). A total of 80 (68%) cancer specialists also offered combined follow-up clinics with other specialties. Clinical examinations for hospital based follow-up were mainly performed by doctors (67% for scheduled regular appointments and 63% for patient initiated appointments) while telephone follow-up was provided in the majority by nurses (76%). Most respondents provided routine tests (76/117 (65%)), from which 66/76 (87%) reported carrying out surveillance tests for ovarian cancer, 35/76 (46%) for cervical cancer, 8/76 (11%) for vulval cancer and 7/76 (9%) for endometrial cancer. Usually patients were discharged after five years (82/117 (70%)), whereas three (3%) were discharged after four years, nine (8%) after three and one (1%) after two years.

Conclusions
Practice varied but most used a standard hospital based protocol of appointments for five years and routine tests were performed usually for women with ovarian cancer. A minority utilised nurse led or telephone follow-up. General Practitioners were rarely involved in routine care. A randomised study comparing various models of follow-up could be considered.

273 words

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Article summary

Article focus

- Follow-up after treatment for cancer is a resource intense area of clinical practice which does not have clear benefits for patients.
- Doctors and nurses involved in care for women with gynaecological cancer were invited to respond to a questionnaire survey.
- A survey is presented of current follow-up after treatment for gynaecological cancer in the UK.

Key messages

- There is a variation of follow-up practice throughout the UK.
- A minority used nurse led or telephone follow-up as opposed to a conventional series of hospital outpatient appointments to see a doctor.

Strengths and limitations of this study

- A strength is that this is the first study to report the extent of patient initiated, specialist nurse or telephone follow-up for gynaecological cancer in the UK.
- L~~A l~~imitations are ~~is~~ that four UK cancer networks did not respond, there were variations of responses within networks and the response rate could not be calculated.

Data sharing statement

The raw data has been archived at NWORTH Clinical Trials Unit and will be available to interested researchers by agreement with the Principal Investigator.

Introduction

Traditionally, patients who have had treatment for cancer are kept on regular review in hospital out-patient clinics for a period of between five to 10 years after completion of their treatment (Kew and Cruickshank, 2006). The aims may be to detect recurrence of tumour, to monitor late effects of treatment, to collect data and to offer patients an opportunity to raise concerns or anxieties arising from their cancer (Kerr-Wilson and McCrum, 1995; Kew *et al,* 2007; Kew *et al,* 2011). The assumption behind this approach is that early detection of recurrence will be of benefit to patients (Lajer *et al,* 2012; Vistad *et al,* 2012) and that monitoring side-effects and anxieties will allow helpful interventions that will improve quality of life.

Routine follow-up is a time-consuming and expensive process with many hundreds of patients attending clinics in each hospital each year at an NHS tariff of £118 per visit (Department of Health, 2011). In Wales alone we estimate the cost of this follow up is in excess of £1m annually. If the object is the early detection of recurrent disease, studies investigating recurrence for breast cancer reported most recurrences presenting between scheduled clinic appointments (Brøyn and Frøyen, 1982; Grunfeld *et al*, 1996; Pandya *et al*, 1985; Scanlon *et al*, 1980; Winchester *et al*, 1979; Zwaveling *et al*, 1987). This is also seen with patients having had treatment for early stage endometrial and cervical cancers (Shumsky *et al,* 1994; Vistad *et al,* 2011). G~~and~~ynaecological patients may wait for their next routine appointment to disclose their symptoms (Olaitan *et al*, 2001). There is no prospective randomised evidence to suggest follow-up improves survival for ovarian cancer (Kew *et al,* 2011) or~~and retrospective data only to guide follow-up strategies~~ for cervical cancer (~~Kew *et al,* 2011;~~ Elit *et al,* 2009). Also there is no evidence that intensive follow up improves survival for endometrial cancer (Agboola *et al,* 1997; Allsop *et al,* 1997; Gadducci *et al,* 2000; Owen and Duncan, 1996; Reddoch *et al,* 1995; Salvesen *et al,* 1997; Shumsky *et al,* 1994). A cost benefit analysis for endometrial carcinoma showed that one asymptomatic recurrence was detected in every 653 consultations (Salvesen *et al*, 1997). In a review of 12 studies, only 30% of endometrial cancer recurrences were asymptomatic and methods of follow-up were unrelated to survival (Fung-Kee-Fung *et al,* 2006). As around 20% of all female cancer survivors have had gynaecological malignancy a cost effective form of surveillance is important (Salani *et al,* 2011).

In clinical practice there appears to be no rationale available for any particular follow-up protocol (Sartori *et al,* 2010). As there is a lack of any demonstrable survival benefit for the follow-up of gynaecological cancer patients, other schedules of care could be considered. ~~Rapid access to oncological assessment at recurrence may be more important than offering frequent routine appointments. Given that patients wish to be cured of their disease and that different schedules of follow-up do not appear to have an impact upon survival, delegation of routine follow-up could be to other carers.~~ Telephone consultations can free oncologists' clinic time and is convenient for patients. Follow-up may be in primary care, a hospital based nurse led clinic, by telephone or at the request of the patient. Despite its place in standard healthcare the benefits of routine follow-up following treatment for gynaecological cancer has received little scrutiny and has rarely been subjected to formal assessment.

In order to determine a baseline of current practice for gynaecological cancer follow-up in the United Kingdom, we have performed a survey of cancer follow-up in gynaecological oncology. The intention is

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to investigate who performs follow-up, for what duration and how this is achieved to see if there is a possibility to improve the quality of care offered to patients after their cancer treatment.

Materials and methods

The follow-up survey was designed using the Bristol Online Survey (BOS) to provide electronic data capture and data management support to the questionnaire. The BOS is an easy-to-use survey tool, which allows developing, deploying and analysing surveys via the internet. The dataset was managed by the Information Systems Department at the North Wales Organisation of Randomised Trials (Bangor University). Data was anonymised and then exported to the databases held in SPSS ™ (version 18.0; SPSS, Chicago, IL). The e-survey targeted gynaecological cancer secondary care practitioners (incorporating surgical and non-surgical specialists) in all cancer networks in the United Kingdom. It was available online using an electronic web link from June to September 2012. An initial invitation email and a reminder with the web link were sent through the Principal Investigator (PI) distribution list to all 441 members of the British Gynaecological Cancer Society (BGCS) and all 71 members of the National Forum of Gynaecological Oncology Nurses (NFGON). A news release published in June 2012 on the BGCS website also invited members to take part in the survey. It is possible that respondents could provide multiple replies but no two responses from the same network were identical.

The investigators in consultation with the BGCS and a patient representative designed the questionnaire which was organised around three themes (see questionnaire in appendix). The first comprised questions related to practice setting (i.e. organisation and hospital) and respondent characteristics (i.e. profession and medical specialty). The second comprised questions related to the use of standard protocols for follow-up. The bulk of the questionnaire addressed information about the different schedules of follow-up and which surveillance tests were used routinely in follow-up practices for different ~~type of~~ cancers. We listed four possible types of follow-up appointments; clinician led (traditional), nurse led, telephone follow-up and patient initiated follow-up. Telephone follow-up appointments were defined as a pre-arrangement for a member of the cancer team to contact the patient by telephone without a need for the patient to attend hospital. Patient initiated follow-up was defined as practice where the patient is not followed-up in secondary care but seen only if the patient requests or initiates a contact, for example if they are worried about a suspicion of recurrent disease.

Most answers were recorded as a binary variable (yes/no answer) with additional, open text box response options throughout the questionnaire for comments and alternative suggestions.

Data was collated and presented as numbers and a percentage of positive responses. For those questions composed of a subset of questions, the number of positive responses in the main question was used as the denominator for the subset. The geographical spread of responses was mapped by calculating responses also on a network basis, grouping all answers from respondents within their cancer networks. Any positive response within the group was accepted as a positive network response. Textual answers were categorised and counted.

Results

Sample size and respondents characteristics

Responses were received from 118 experts in gynaecological cancer drawn from the membership of the BGCS and NFGON. Because the survey was conducted online with the request to take part distributed widely by email it is impossible to state how many had the opportunity to take part but did not. Therefore the response rate has not been calculated. Nonetheless we received responses from 86% (24/28) of the cancer networks in England and all cancer networks in Scotland (three), Wales (two), and Northern Ireland (one). Each responding cancer network provided between one to 14 responses. One response was received from a surgical oncologist based in Greece who has been excluded from the study as the objective is assessing current practice of follow-up after gynaecological cancer treatment in the UK. Of the 117 respondents included in the study, 71 (61%) worked in a cancer centre, 32 (27%) in a cancer unit and 12 (10%) reported working in both. Eighty-eight (75%) of the respondents specialised~~w~~ in~~ere~~ surgical oncology~~ists~~. Fifteen (13%) specialised in ~~were~~ clinical oncology~~ists~~ and six (5%) ~~were specialised~~ in medical oncology. The majority of the respondents (83 (71%)) were doctors while nurses constituted less than a third of the sample (32 (27%)). Full results are presented in table 1.

Standard follow-up protocols

All respondents with the exception of one surgical oncologist (116/117 (99%)) had a standard follow-up protocol after completion of treatment. However all 30 networks providing responses had at least one respondent reporting having protocols for follow-up. The vast majority of respondents provided follow-up in secondary care, only two respondents (from different English cancer networks) reported that visits to primary care are part of their follow-up routine.

Most 87/116 (75%) of the respondents reported using different follow-up protocols for different tumour sites (eg. cervix and ovary) and 35/116 (30%) reported having different protocols for different tumour types (eg. well or poorly differentiated). On a cancer network basis, different protocols for different tumour sites were reported from 29/30 (97%) networks. Different protocols for different tumour types were reported by respondents from 17/30 (57%) networks.

Composition follow-up appointments

All respondents in our sample reported they follow-up patients after completion of gynaecological cancer treatment. One hundred and fifteen (98%) reported hospital scheduled regular follow-up appointments from which the patient may be discharged if she remains disease free after a specified period of time. This follow-up was augmented or replaced by a telephone follow-up in 29 (25%) and patient initiated appointments in 38 responses (32%). A combination of all three forms of follow-up was reported by 11 respondents (a total of 54 respondents offered more than one modality of follow-up). Of these 18/54 (33%) reported that patients have an opportunity to attend either a medical or a

nurse led clinic. However, 6/18 (33%) did not have a protocol to allocate patients to each clinic. For patient initiated appointments, 10/38 (26%) did not have a protocol with contact details (eg. a secretary, Macmillan nurse or General Practitioner) for self-referrals. A total of 80/117 (68%) cancer specialists from 27/30 networks (90%) also offered combined follow-up clinics with other specialties (eg. combined surgical and medical oncology or surgical and clinical oncology clinics).

Virtually all respondents reported in the case of sudden events that symptomatic patients could arrange an appointment in less than two weeks. Seven (6%) respondents from five different cancer networks answered that their practices schedule urgent appointments in a period of two to four weeks, from which two of them also scheduled urgent patient initiated appointments in the same timeframe.

Follow-up in hospital was mainly performed by doctors (67% for scheduled regular appointments and 63% for patient initiated appointments) while telephone follow-up care was provided in its majority by nurses (76%). Full details are illustrated in table 2.

Duration of follow-up and surveillance tests

The survey asked respondents whether they perform any type of routine surveillance test during follow-up. Routine tests were requested by 65% (76/117) of respondents, from which 87% (66/76) requested tests for ovarian cancer, 46% (35/76) for cervical cancer, 11% (8/76) for vulva cancer and nine per cent (7/76) for endometrial cancer. In addition, respondents were asked to provide details of when these tests are performed but only a few responses were obtained. Table 3 shows the distribution of the different type of tests employed during follow-up.

CA125 measurement was the most frequently used test (60/66 (91%)) during follow-up of ovarian cancer patients. Other blood tests (8/66 (12%)), e.g. alpha-fetoprotein , carcino-embryonic antigen , CA19.9 and inihibin were also requested. The routine use of computed tomography and magnetic resonance imaging (MRI) scans for ovarian cancer were reported by 9/66 (14%) of the respondents (one respondent used both CT and MRI). Eight respondents stated the CA125 test is performed at each visit. Another seven reported the CA125 is performed every three months for the first year after completion of treatment, from which two reported they carry on with routine testing for the second year and four up to the fifth year every six months.

The use of MRI (15/35 (43%)) was the most common investigation employed in the follow-up of cervical cancer with cervical or vaginal cytology being the second commonest method (14/35 (40%)). There was a wide variety of tests (8/35 (23%)) reported in the follow-up of this type of cancer. Two of the respondents stated they perform vault cytology for cervical cancer patients annually for a period of five years following hysterectomy, while three specialists reported carrying out the test at six and 18 months post-treatment.

Most respondents discharged their patients after five years of follow-up (82/117 (70%)), three (3%) after four years, nine (8%) after three and one (1%) after two years whereas 22/117 (19%) of respondents did not answer this question.

Discussion

The current survey is the first evidence reporting the extent of patient initiated, specialist nurse or telephone follow-up for gynaecological cancer in the UK. There were no respondents for four cancer networks and because the survey was online, a response rate could not be calculated. Whilst we know the membership of the professional societies invited to respond, we do not know whether the entire membership received or read their invitations to participate in our survey. Nonetheless a low response rate~~This~~ could introduce a potential source of bias if the answers from respondents were not representative of their relevant professional communities. Different protocols for different tumour sites and types and the use of combined speciality follow-up clinics were more often reported from network responses than for individual responses because positive network responses included respondents with at least one positive response in each network. Unfortunately we could not calculate the agreement level within networks because of the small numbers of respondents from each network. The lack of consistency of responses within networks is again a potential source of error as such responses may not accurately reflect local practice. We did not review the content of the follow-up protocols and so we cannot verify if these variations represent locally approved practice within each network. Network guidelines may be adapted for local use or not followed exactly, so variation within networks would be expected. Our survey shows that all gynaecological cancer networks providing responses have protocols for follow-up after treatment. Follow-up for patients treated for gynaecological cancer is mainly performed by doctors in secondary care. Patient initiated follow-up was offered by 32% of respondents and telephone follow-up was offered by 25%. A large minority of patient initiated follow-up and combined follow-up schedules did not have protocols to guide practice. The most common duration of routine follow-up was for five years. There are few routine tests undertaken during follow-up to detect recurrence and they show no consistency particularly for cervical cancer. Of the 35 respondents who requested tests for cervical cancer follow-up, 15 (43%) requested MRI and 14 (40%) requested cytology. However, cervical cytology is recommended for the follow-up of early stage cervical cancer if the cervix is conserved and was based upon expert opinion rather than upon evidence (Luesley and Leeson, 2010) V~~Such v~~ariation in the routine use of tests during follow-up is not surprising with the lack of evidence to guide clinical management. The exception is CA125 testing following treatment for ovarian cancer where 52% of all respondents recommended CA125 monitoring despite grade one evidence to demonstrate that routine CA125 measurements do not provide a survival benefit with early treatment of relapse~~benefit asymptomatic patients having had ovarian cancer~~ (Rustin *et al,* 2010). Furthermore, there appears to have been no recent change of this practice in our survey, as monitoring with CA125 testing was reported in 24 of the 34 UK networks (71%) whereas 67% of networks recommended such testing in an earlier survey (Kew and Cruickshank, 2006). Respondents were asked not to include tests requested during treatment but tests could have been included as part of trial protocols. Vistad *et al* (2012) also published results of a web-based survey of practice amongst gynaecological oncologists across Europe and reported that 47% of the 375 respondents considered follow-up with General Practitioners to be acceptable. Other options for care were not considered and the response rate was thought to be below 20%. ~~However there appears to be little or no evidence upon which to guide follow-up for gynaecological malignancy from the survey by Vistad *et al,* the earlier survey from the UK (Kew and Cruickshank, 2006) and from our work.~~

From other research, patients with previous ovarian cancer rated CA125 testing as the most important part of follow-up (Kew *et al,* 2009). ~~despite the knowledge that routinely measuring the CA125 value~~

~~does not improve survival (Rustin *et al,* 2010).~~ Furthermore knowledge of recurrence whether treatable or not appears useful to patients (Papagrigoriadis and Heyman, 2003) and information should be provided to detail the scope and limitations of follow-up (Kew *et al,* 2007). Rapid access to oncological assessment at recurrence may be more important than offering frequent routine appointments (Shumsky *et al,* 1994; Gulliford *et al,* 1997). ~~Given that patients wish to be cured of their disease and k~~Knowing that different schedules of follow-up do not have an impact upon survival, delegation of routine follow-up could be to other carers (Vistad *et al,* 2012). Follow-up may be in primary care, a hospital based nurse led clinic, by telephone or at the request of the patient. An individualised approach to follow-up is likely to be important to concentrate care for those perceived to be at a greater risk of recurrent disease or other issues of survivorship. This may include ~~a~~ risk stratification~~assessment~~ where there are effective interventions for physical, psychological and social issues as well as needs assessments which are clearly patient centred as defined by the National Cancer Survivorship Initiative (Watson *et al,* 2012). ~~whilst bearing in mind that a minority of patients may be cured with further therapy.~~ Follow-up has to be multidisciplinary, designed for detection~~risk~~ of morbidity as well as recurrence and with good communication between professional groups. Informed patient choice regarding mode and frequency of follow-up is important. Reducing the frequency of follow-up appointments may not place an increased demand upon unnecessary patient initiated extra hospital appointments and patients may prefer fewer appointments (Gulliford *et al,* 1997). The ideal time of advising a patient about a preferred form of follow-up is unclear but may be shortly after all modalities of treatment have been completed.

Healthcare providers should be informed by prospective data on the validity of alternative strategies for gynaecological cancer follow-up which is already a minority part of current UK practice. The North Wales Organisation for Randomised Trials in Health in collaboration with several leading gynaecological oncologists has previously developed a proposal for a randomised study to assess the value of hospital follow-up of endometrial cancer (Follow-up in Gynaecological Cancer Units: RCT for Endometrium or FIGURE). The proposal was for a multicentre, randomised trial comparing standard (hospital) follow-up with patient initiated review. The endpoints were to be quality of life and survival with a planned recruitment of 2200 patients to detect an effect size of 0.2. Unfortunately, although the proposal was well received, it was impossible to agree a level of funding to allow the study to proceed. More recently the Endometrial Cancer Telephone Follow-up Trial (ENDCAT ISRCTN 75220876) has started. This is a study comparing traditional hospital follow-up with telephone follow-up by specialist gynaecology oncology nurses with primary outcomes of psychological morbidity and patient satisfaction. Again this is a randomised trial for endometrial cancers only and is at a single centre. It is currently recruiting to schedule and is due to close in 2014. A Trial between Two Follow-up Regimens with Different Intensity in Endometrial Cancer Treated Patients (TOTEM NCT00916708) is a further ongoing but multicentre randomised trial in Italy, comparing overall survival, progression free survival, complications, proportion of asymptomatic relapse and the proportion of patients completing each regimen for follow-up. It is due to close in 2015.

Our study has demonstrated that the vast majority of follow-up still reflects traditional patterns, with only about a third of practitioners incorporating more flexible follow-up routines. However, the evidence base for changing practice to a less intensive follow-up programme for gynaecological cancer is poor and Vistad *et al* (2011) reported no randomised studies on this subject. A trial similar to an early version of FIGURE should be revisited ~~but~~ which ~~to~~ included follow-up for more than one gynaecological cancer site. In the present constrained financial environment, to continue to use

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patterns of follow-up for gynaecological cancers which are neither evidence-based nor affordable is inappropriate. A multicentre randomised controlled trial could assess the clinical benefits and costs of routine hospital follow-up in comparison with the patient being empowered to choose her preferred format of follow-up for most gynaecological cancers. The current survey may inform design of such a trial by providing data from the UK concerning national practice.

3252 words

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Authors' roles

Simon Leeson	final manuscript preparation, review of data, design of questionnaire
Nick Stuart	draft script development, design of questionnaire
Yvonne Sylvestre	review of data
Liz Hall	draft script development
Rhiannon Whitaker	draft script development, review of data, design of questionnaire

Table 1: Characteristics of respondents (N=117)

	N (%)
Region	
England	102 (87%)
Wales	7 (6%)
Scotland	5 (4%)
Northern Ireland	3 (3%)
Organisation	
Cancer centre	71 (61%)
Cancer unit	32 (27%)
Cancer unit & cancer centre	12 (10%)
Other[1]	2 (2%)
Specialty	
Surgical oncology	73 (62%)
Medical oncology	6 (5%)
Clinical oncology	15 (13%)
Surgical & medical oncology	6 (5%)
Surgical & clinical oncology	1 (1%)
Surgical, medical & clinical oncology	8 (7%)
Other[2]	8 (7%)
Profession	
Medical	83 (71%)
Nursing	32 (27%)
Other[3]	2 (2%)

1. Includes gynaecology unit in a chemotherapy centre (n=1) and hospital (n=1).
2. Includes clinical nurse specialist (n=2), nursing (n=2), gynaecology (n=2), gynaecology & surgical oncology (n=1) and pathology (n=1).
3. Includes consultant radiographer (n=1) and missing response (n=1).

Table 2: Type and frequency of occurrence of differing modes of follow-up

	Regular	Telephone	Patient initiated
Positive responses	115/117 (98%)	29/117 (25%)	38/117 (32%)
Urgent follow-up bookings			
< 2 weeks	108/115 (94%)	29/29 (100%)	35/38 (92%)
2 to 4 weeks	7/115 (6%)	0 (0%)	2/38 (5%)
Responsible for follow-up			
Doctors	77/115 (67%)	4/29 (14%)	24/38 (63%)
Nurses	0 (0%)	22/29 (76%)	2/38 (5%)
Doctors & nurses	36/115 (31%)	3/29 (10%)	11/38 (29%)
Other[1]	2/115 (2%)	1/29 (3%)	1/38 (3%)

1. Includes radiographer (n=1), consultant radiographer (n=1), for regular appointments; specialist radiographer (n=1) for telephone appointments and missing response (n=1) for patient initiated appointments.

Table 3: Frequency of surveillance tests reported by type of test and cancer type

	Ultrasound†	CA125	Other blood tests*	CT	MRI	Cytology	Other¶	Total
Ovarian	5	60	8	5	4	0	0	82
Cervical	1	0	4	0	15	14	3	37
Endometrial	1	1	0	0	1	1	0	4
Vulval	0	0	0	0	1	0	4	5

Key: CA125, cancer antigen 125; CT, computed tomography; MRI, magnetic resonance imaging.
† Ultrasound includes: abdominal and transvaginal ultrasound.
** Other blood tests includes: other tumour markers (n=8) for ovarian cancer and squamous cancer antigen (n=3) for cervical cancer.*
¶ Other includes: colposcopy (n=2) for cervical cancer and vulvoscopy (n=3) for vulval cancer.

Appendix: Gynaecological cancer follow-up survey of current practice

Introduction

Patients may appreciate the attention given to follow up after treatment for cancer yet the survival benefit of follow up is unclear. We are planning to review local practice to determine if follow up to detect recurrence at an early stage can improve survival. However a preliminary assessment of national practice would be ideal. A prospective study of follow up strategies may follow. We would appreciate a few minutes of your time as cancer specialists to complete the following questionnaire.

Questions

Q1. In which cancer network do you work?

Q2. Where do you work?

i. Cancer Centre
ii. Cancer unit
iii. Other (please specify)

Q3.Please enter name of the hospital (s)at which you work? (Optional)

Q4. Is your work within surgical, medical or clinical oncology or another discipline?

i. Surgical oncology
ii. Medical oncology
iii. Clinical oncology
iv. Imaging
v. Pathology
iv. Other (please specify)

Q4.a. What is your profession?

i. Medical
ii. Nursing
iii. Other (please specify)

Q5. Do you have a standard follow up protocol following completion of treatment for gynaecological cancer?

i. Yes
ii. No
iii. Don't know

Q5a. Do you have a different protocol for different tumour sites e.g. cervix and ovary?

i. Yes
ii. No
iii. Don't know

Q5b. Do you have a different protocol for different tumour types e.g. well or poorly differentiated?

i. Yes
ii. No
iii. Don't know

Q5c. Does the routine follow-up involve visits to primary care?

i. Yes
ii. No
iii. Don't know

Q6. Do you have regular follow-up appointments? Regular follow-up appointments here means an agreed schedule of visits from which the patient may discharge if she remains disease free after a specified period of time.

i. Yes
ii. No
iii. Don't know

Q6a. If so, when can you book urgent follow-up appointments for symptomatic patients?

i. In less than 2 weeks
ii. 2-4
iii. 4+ weeks
iv. Don't know

Q6b. Who provides the follow-up?

i. Nurses
ii. Doctors
iii. Don't know
iv. Other (please specify)

Q7. Do you have telephone follow-up appointments? A telephone follow-up appointment is an appointment pre-arranged for a member of the cancer team to contact the patient by telephone without a need for the patient to attend hospital.

i. Yes
ii. No
iii. Don't know

Q7a. If so when can you book urgent follow-up appointments for symptomatic patients?

i. In less than 2 weeks
ii. 2-4
iii. 4+ weeks
iv. Don't know

Q7b. Who provides the follow-up?

i. Nurses
ii. Doctors
iii. Don't know
iv. Other (please specify)

Q8. Do you have patient initiated follow-up appointments? Patient initiated follow-up is when the patent is not followed-up in secondary care but sees only if the patent requests (such as suspicion of recurrent disease).

i. Yes
ii. No
iii. Don't know

Q8a. Do you have a protocol for asking patients to self-refer with contact details (e.g. a secretary, Macmillan Nurse or her GP)?

i. Yes
ii. No
iii. Don't know

Q8b. If so, can urgent appointments for symptomatic patients be booked? To see the patient

i. In less than 2 weeks
ii. 2-4
iii. 4+ weeks
iv. Don't know

Q8c. Who provides the follow-up?

i. Nurses
ii. Doctors
iii. Don't know
iv. Other (please specify)

Q9. Do you have a combination of regular follow-up, telephone follow up and/ or patient initiated follow-up appointments?

i. Yes
ii. No
iii. Don't know

Q9a. Do you have a follow-up where patients attend either a medical or a nurse led clinic?

i. Yes
ii. No
iii. Don't know

Q9b. If yes, do you have a protocol to allocate patents to each clinic?

i. Yes
ii. No

Q10. Do you have combined follow-up clinics with other specialties (e.g. combined surgical and medical oncology, surgical and clinical oncology clinics?

i. Yes
ii. No
iii. Don't know

Q10a. If yes please specify

i. Clinical
ii. Medical
iii. Surgical oncology

Q11. During follow-up do you carry out certain blood tests (e.g. CA125), vault cytology or imaging such as CT or MR routinely for cases at a certain time interval?

i. Yes
ii. No
iii. Don't know

Q11a. Ovary

i. Yes
ii. No

Q11a.i. Please provide details of which tests and when these are usually carried if possible

Q11b. Cervix

i. Yes
ii. No

Q11b.i. Please provide details of which tests and when these are usually carried if possible

Q11c. Endometrium

i. Yes
ii. No

Q11c.i. Please provide details of which tests and when these are usually carried if possible

Q11d. Vulva

i. Yes
ii. No

Q11d.i. Please provide details of which tests and when these are usually carried if possible

Q11e. Other

i. Yes
ii. No

Q11e.i. Please provide details of which tumour site(s)

Q11e.i.i. Please provide details of which tests and when these are usually carried if possible

Q12. After how many years of follow up are patients usually discharged?

i. 1
ii. 2
iii. 3
iv. 4
v. 5
vi. 6
vii. 7
viii. 8
ix. 9
x. 10
xi. 10+
xii. Never
xiii. N/A
xiv. Other(please specify)

Q13. If we were to develop a larger study would your centre be prepared to participate?

i. Yes
ii. No

Q13a. If so please add contact details here or email Simon Leeson